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ABSTRACT

Findings are presented from a project which aimed to estimate the prevalence of developmental disabilities among Navajo children, aged 0-5 years, living in the Navajo Nation; determine what services they and their families require; and recommend policy and practice to assure that needed services are received. Section I provides a description of the project's background and purpose. Section II analyzes and compares prevalence rates based on diagnostic and functional criteria. A prevalence rate ranging from less than 1 percent to about 2.3 percent (100-644 children) is estimated. Services required by children with developmental disabilities and their families are outlined in Section III, and the present status of services, based on an agency survey, is reported. Policy and practice recommendations focus on four areas: underlying values, guiding policy, direct services, and administrative supports. Among recommendations are the desirability of delivering services in the most appropriate setting, coordinating existing resources, promoting community awareness, strengthening the family support system, developing an improved client information system, and developing a Navajo protection and advocacy system. References are included. Appendices describe provisions of the Early Childhood Education Act (Public Law 99-457) and legislation pertaining to the Navajo Trust Fund. (JW)

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A Path to Peace of Mind: Providing Exemplary Services to Navajo Children with Developmental Disabilities and Their Families

Technical Report

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A PATH TO PEACE OF MIND:

PROVIDING EXEMPLARY SERVICES TO NAVAJO CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

TECHNICAL REPORT

1987

RESULTS OF A PROJECT SPONSORED BY:

THE NAVAJO TRIBAL COUNCIL

AND

SAVE THE CHILDREN FEDERATION

A PATH TO PEACE OF MIND:
PROVIDING EXEMPLARY SERVICES TO NAVAJO CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

TECHNICAL REPORT

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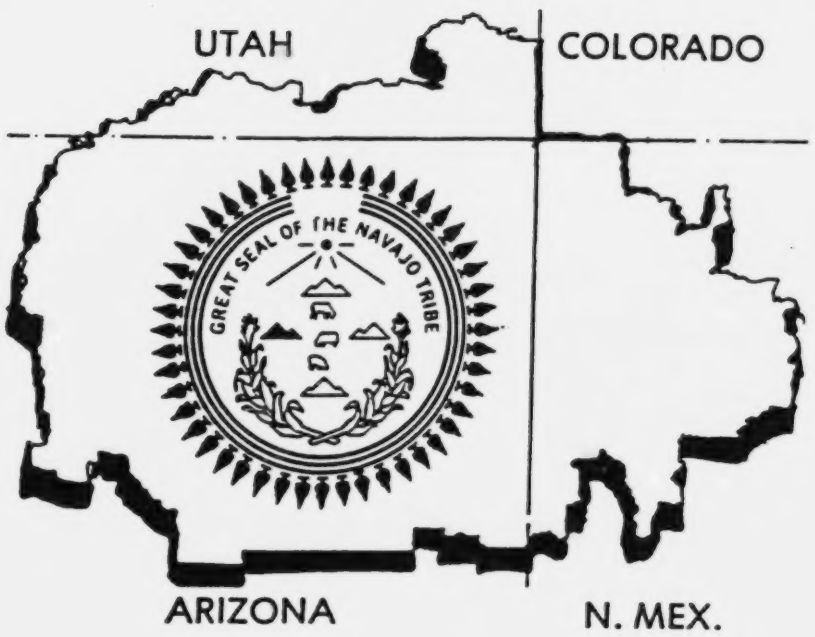
"If we could just keep mindful of the teachings of our grandparents to consider handicapped children as special persons like our holy people, then the path to peaceful minds for our children and ourselves will be found."

A Navajo Parent



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- Those who spoke with us candidly about services presently available in the Navajo Nation for Navajo children with disabilities. So many persons were willing to take time from their day to acquaint us with the complex issues that must be considered;

- Persons who provided us with useful information regarding the status of services for children with disabilities on the Navajo Nation. Some of these persons, like Kathy Fleshman, Jud Cunningham, Susan Bahle and Michael Brantley, sent us information or offered guidance. Others completed and returned survey forms designed to gather specific types of information;

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We are particularly grateful to the many family members who took time from their day to attend the family forum and to participate in family interviews. These activities were held to explore family circumstances and needs. By sharing their personal experiences, these family members did much to document the need for improved services in the Navajo Nation and to guide the design of such services.

This report is dedicated to all Navajo families who provide or have provided care at home to a family member with a developmental disability.

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SECTION I: BACKGROUND TO THE PROJECT AND PROJECT PURPOSE

A. Project Background

In November of 1984, the Navajo Tribal Council and its Chairman, Peterson Zah, challenged Save the Children Federation (SCF) to help the Tribe improve services for children with developmental disabilities living on or near the Navajo Nation. In accepting this challenge, SCF staff sought the advice and assistance of tribal officials, service providers, advocates and others. These intial discussions culminated in a jointly funded project, the subject of this report. The report presents findings emerging from the project and offers 16 policy recommendations relative to the needs of children with disabilities aged 0-5 years and their families. A summary of project activities and findings may be found in the "executive summary" or "fact sheet," available through SCF.

B. Project Purposes and Objectives

In recent decades, the norms and mores affecting family life have undergone rapid changes. Parents of children with developmental disabilities have also endured these changes and have also experienced significant shifts in the way society responds to children with disabilities.

Until recently, children with developmental disabilities were not entitled to a public school education. The passage of The Education for All Handicapped Children Act (PL 94-142) in 1974 changed these circumstances, making such children aged 5-21 years eligible for public school services, if their state elected to participate in the program. The Bureau of Indian Affairs (BIA) is a participant in this program, given its recognition as a "51st state" for purposes of implementing this law. With New Mexico coming on board in 1985, all states now offer public school services to children with developmental disabilities aged 5-21 years. Pushing this initiative further, a recent federal mandate (shown in Appendix A), The Early Intervention Act of 1986 (PL

99-457), mandates that public schools soon begin serving children with disabilities from birth through five years of age. Finally, Headstart programs, serving children aged 3-5 years must serve a number of children with disabilities totalling 10% of those served.

Though these initiatives, aimed directly at children with disabilities, are welcomed, recognition of the family's role in providing home care has been slower to evolve. Nearly all children with developmental disabilities spend the early stages of their lives with their families. Yet until recently parents were afforded only two residential options: they could forego traditional parental functions by placing their child in a residential facility or they could provide care at home with little or no external support. A third option, however, is slowly evolving around the country whereby families could provide home care while receiving services to support and enhance their efforts.

During a 1984-85 national survey (Agosta, Jennings & Bradley, 1985) it was found that about 25 states offer what may be termed "extensive" services. Though it is clear that most of these statewide systems are embryonic and somewhat fragile enterprises, offering few services to relatively few families, the emerging commitment among policy makers to support families is irrefutable. Most statewide programs have been initiated since 1980 and numerous state are setting plans for re-shaping existing programs, or initiating new pilot or statewide efforts. Family support initiatives relevant to this project include those modest efforts undertaken in states in which the Navajo Nation holds land, including Arizona, New Mexico and Utah. Each of these states have begun to offer small numbers of families certain support services.

Consistent with these trends, affecting both children with disabilities and their families, the purpose of this project is to identify means for serving Navajo children with developmental disabilities aged 0-5 years and their families. To achieve this end, three objectives were set:

- Estimate the prevalence of developmental disabilities among Navajo children aged 0-5 years living in the Navajo Nation;
- Determine what services they and their families require; and
- Recommend policy and practice, involving existing resources to the extent feasible, to assure that needed services are received.

SECTION II: THE PREVALENCE OF DEVELOPMENTAL DISABILITIES AMONG NAVAJO CHILDREN AGED 0-5 YEARS

A. Conceptual Overview

The size of the developmental disabilities population can be represented in terms of incidence or prevalence. Incidence refers to the number of new cases that are evident during a specified period of time. In contrast, prevalence refers to the number of cases (old and new) that are present in a population for a designated time interval or point in time.

Establishing the prevalence of developmental disabilities among very young children is a complex task, burdened by:

- definitional ambiguities whereby the term "developmental disability" is not defined consistently among professionals;
- cultural perspectives that may well influence how family members or professionals perceive a "disabling" condition;
- an unwillingness among some to apply a label such as "developmental disability" to children so young;
- problems with identifying the presence of a disabling condition and/or its impact on the child; and
- uncertainties regarding the long term impact of a disabling condition on the child.

As a result, many children with developmental disabilities are identified only as they grow older and their disability becomes more apparent or is "caught" by observant professionals (e.g., school teachers). Others, without disabling conditions initially, incur a disability later in life due to disease, injury, or other trauma.

Numerous definitions of "developmental disability" exist because existing laws allow each state to adopt its own. In fact, only about 25 states use the federal definition of the term exclusively and it is not uncommon for state agencies operating within the same state to use differing definitions to determine whether an individual is eligible for services. This issue is of particular importance to this project because the Navajo Nation holds land in

three states, namely, Arizona, New Mexico and Utah.

One fundamental difference between competing definitions pertains to HOW "disability" is defined. Existing definitions may be classified as either as categorical or funtional. Categorical definitions are based in a determination of the type of disabling condition possessed or incurred, while functional definitions rely on an assessment of the severity of the disabling condition (i.e., its impact on the individuals capacity to function).

Often, where categorical definitions are employed medical diagnoses are used as the primary means of classification. For instance, in several states, including Arizona, persons classified as having a "developmental disability" must have either autism, cerebral palsy, epilepsy or mental retardation. As depicted by Figure 1, persons having other types of disabling conditions (e.g., cystic fibrosis) are not considered to have a "developmental disability." Further, this type of definition ignors the severity of the disabling condition or its impact on the individual's capacity to perform daily living skills; all persons found to have one of the key disabling conditions are included.

Figure 1: Mechanics of Categorical Definitions of Disability *

	Disability Categories				
Severity Level	Mental Retardation	Cerebral Palsy	Autism	Epilepsy	Other Conditions
Mild Moderate Severe Profound	ALL PERSONS CATEGORICALLY ELIGIBLE REGARDLESS OF LEVEL OF SEVERITY				ALL PERSONS CATEGORICALLY EXCLUDED REGARDLESS OF SEVERITY

* Source: Brehon Institute for Human Services, 1985.

Using this approach, the number of children found to have a "developmental disability" will vary dependent on the diagnostic categories chosen to define the term and the effectiveness of the means used to screen children for disability. Moreover, it must be understood that all children experiencing

delays in their development are not identified intially on the basis of a medical diagnosis. These children, who could well benefit from early intervention services, may easily slip past diagnostic screening practices.

Functional definitions of "developmental disability" take into consideration the individual's capacity to perform daily living activities. The federal definition of the term, shown by Figure 2, takes this approach, though it also applies limits to the types of disabling conditions considered and invokes certain other conditions (e.g., age of onset of the disabling condition). In contrast to Arizona, New Mexico and Utah both use functional definitions of "developmental disabilty," tailored after the federal model.

Figure 2: The Federal Definition of Developmental Disability

The Comprehensive Services and Developmental Disabilities Amendments of 1978 (Public Law 95-602; Section 102(7)) specifies that the term "developmental disabilities" means a severe chronic disability of a person which:

a. Is attributable to a mental or physical impairment or combination of mental or physical impairments;

b. Is manifested before the person attains age twenty-two;

c. Is likely to continue indefinitely;

d. Results in substantial limitations in three or more of the following areas of life activity:

1. Self Care,
2. Receptive and Expressive Language,
3. Learning,
4. Mobility,
5. Self Direction,
6. Capacity for Independent Living, and
7. Economic Self Sufficiency; and

e. Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

The above stated federal definition, however, seems more suited to adolescents and adults than children, given a child's inherent limitations in the life activities specified. As a consequence, several states have devised definitions tailored to children that consider the risk of such limitations developing if treatment were withheld. For example, the New Mexico Department of Education views a child as having a "developmental disability" if the child:

> "is at risk of having a developmental disability. Those considered "at risk" must have an organic or congenital condition (e.g., Downs Syndrome) that has a high predictability of requiring intensive intervention and will significantly impair the child's functioning without intervention." (New Mexico State Department of Education, 1986).

Likewise, the Utah Division of Services to the Handicapped requires that children entering early intervention programs must be either: 1) screened using the Battelle Sceening Test, a standardized measure designed for young children, and found to have significant functional limitations or developmental delays, or 2) found to have a genetic or physiological condition which could cause the child to be developmentally delayed. Though not considered exhaustive, a list of such conditions compiled by Utah state staff is displayed by Figure 3. Used in tandem, these two practices are meant to identify both children who are already experiencing significant functional limitations and others who are at risk of developing such limitations.

Typically, when a functional approach to defining disability is taken only those found to have "significant" functional limitations or at risk of such limitations are classified as having a "developmental disability." As shown by Figure 4, this approach permits persons with a wide variety of disabling conditions to be classified as having a "developmental disability," but excludes those with relatively mild functional limitations.

Essential to a functional approach is judgement regarding the impact or potential impact of a disabling condition on a child's capacity to function.

Figure 3: Diagnostic Conditions Used in Utah to Identify Children with Developmental Disabilities*

* Note: The list below is not exclusive. Other diagnoses may suffice.

Albright Hereditary Osteodystrophy Syndrome
Amyoplasia Congenita Disruptive Sequence
Aniridia-Wilms Tumor Association
Autism
Borjeson-Forssman-Lehmann Syndrome
Camptomelic Dysplasia Syndrome
Carpenter Syndrome
Cat-Eye Syndrome
CHARGE Association
Coffin-Lowry Syndrome
Coffin-Siris Syndrome
Cohen Syndrome
Cryptophthalmos Syndrome
De Lange Syndrome
Distal Arthrogryposis Syndrome
Down Syndrome
Dubowitz Syndrome
Femoral Hyoplasia-Unusual Facies Syndrome
Fetal Methyl Mercury Effects
Fetal Rubella Effects
Fragile X
Freeman-Sheldon Syndrome
Generalized Gangliosidosis Syndrome (I)
Gillian Turner TYpe X-Linked Mental Deficiency
Hearing Loss
Hecht Syndrome
Holoprosencephaly Sequence
Homocystinuria Syndrome
Hurler Syndrome
Hurler-Scheie Compound Syndrome
Incontinentia Pigmenti Syndrome
Johanson-Blizzard Syndrome
Langer-Giedion Syndrome
Laurence-Moon Biedl Syndrome
Leprechaunism Syndrome
Leroy I-Cell Syndrome
Linear Sebaceous Nevus Syndrome
Lowe Syndrome
Macrocephaly
Marinesco-Sjogren Syndrome
Maroteaux-Lamy Mucopolysaccharidosis Syndrome
Maternal PKU Fetal Defects
Melnick-Fraser Syndrome
Menkes Syndrome
Microcephaly
Mietens Syndrome
Miller-Dieker Syndrome
Morquio Syndrome
Opitz Syndrome
Opitz-Frias Syndrome
Partial Trisonomy 10q Syndrome
Pena-Shokeir Syndrome (I)
Pena-Shokeir Syndrome (II)
Prader Willi Syndrome
Pseudo-Hurler Polydystrophy Syndrome
Rhizomelic Chondrodysplasia Punctata
Roberts Syndrome
Rothmund-Thomson Syndrome
Rubalcaba-Myhre Syndrome
Rubinstein-Taybi Syndrome
Ruvalcaba Syndrome
Sanfilippo Syndrome (A & B)
Scheie Syndrome
Schwartz Syndrome
Seckel Syndrome
Septo-Optic Dysplasia Syndrome
Sjogren-Larsson Syndrome
Smith-Lemli-Opitz Syndrome
Sotos Syndrome
Steinert Myotonic Dystrophy
4p Syndrome
5p Syndrome
6p Syndrome
9 p Syndrome
13q Syndrome
18p Syndrome
18q Syndrome
Triploidy Syndrome
Triploidy/Diploidy Mixoploidy
Trisonomy 4 Syndrome
Trisonomy 8 Syndrome
Trisonomy 9 Syndrome
Trisonomy 9 Mosaic Syndrome
Trisonomy 9p Syndrome
Trisonomy 13 Syndrome
Trisonomy 18 Syndrome
Trisonomy 20p Syndrome
Trisonomy 21 Syndrome
Weaver Syndrome
Williams Syndrome
X-Linked Hydrocephalus Syndrome
XXXX Syndrome
XXXXX Syndrome
XXXY and XXXXY Syndromes

Though a few children have disabilities so severe that they are easily classified as having a developmental disability, others manifest conditions that are not so easily judged.

Two issues left unresolved pertain to: 1) how functional capacities of young children can be measured reliably, especially in face of crucial cultural factors such as those apparent in the Navajo Nation, and 2) the level of functional limitation used to determine the presence of a "developmental disability." As suggested by Figure 4, the number of those found to have a "developmental disability" will vary dependent on where this level is set.

Figure 4: Mechanics of Functional Definitions of Disability *

	Disability Categories				
Severity Level	Mental Retardation	Cerebral Palsy	Autism	Epilepsy	Other Conditions
Mild	INCLUDES ALL CONDITIONS BUT EXCLUDES THOSE WITH MILD OR MODERATE FUNCTIONAL LIMITATIONS (DIVIDING LINE CAN BE ADJUSTED!!!)				
Moderate					
Severe	INCLUDES ALL CONDITIONS AND ALL THOSE WITH SEVERE OR PROFOUND FUNCTIONAL LIMITATIONS				
Profound					

* Source: Brehon Institute for Human Services, 1985.

Given these considerations, estimating the prevalence of "developmental disabilities" among young Navajo children is a troublesome task. What definition of the term ought to be used as the basis for computing prevalence estimates? While Arizona primarily uses a categorical definition of the term, New Mexico and Utah use functional definitions tailored after the federal model. Yet the New Mexico and Utah definitions are not identical.

Complicating matters is the Navajo culture. The absence of a word for "disability" in the Navajo language and the resulting implications has generated much important discussion (e.g., Fischler & Fleshman, 1985; Toubbeh, 1986; Joe, 1980) and strikes at the core of the issue. What is viewed as a

"severe disability" by some Navajo, is not entirely noticed by others. Likewise, given the variance in environmental context in the Navajo Nation, persons who appear to have significant functional limitations in one place (e.g., the classroom) may not appear so limited when when seen elsewhere (e.g., working on the family ranch). This cultural perspective is not only reflected in the definition of "developmental disability," but also in the estimate of the prevalence of such disability.

In the absence of a definition of "developmental disability" grounded in the Navajo culture and in view of the competing definitions used in the three relevant states, project staff did not compute prevalence estimates based on any one definition. Rather, information based on both diagnostic and functional criteria was gathered, analyzed and compared, yielding multiple rates that vary according to the definitional criteria used.

Pursuant to these ends, project staff undertook three tasks: 1) review of available literature, 2) analysis of information on the diagnoses applied to Navajo children 0-5 years, and 3) analysis of information on the functioning levels of Navajo children 0-5 years. Both of the data sets analyzed were compliled by staff at the Gallup Indian Health Service Center.

B. Studies Regarding Navajo Children

Studies on the occurrence of developmental disabilities among children aged 0-5 years in mainstream America place the prevalence rate around one percent for infants and toddlers, and higher for children approaching school age (Ashbaugh, Spence, Lubin, Houlihan & Langer, 1985). In the Navajo nation, the prevalence rate is likely higher, due to contributing socio-economic factors. Some claim that the prevalence rate is as high as 15% (Bernard, 1975), while others suggest that the rate is closer to 2% (Fleshman, 1983a). Two studies of particular note involve examination of the: 1) prevalence of selected diagnostic conditions among Navajo children aged 0-5 years, and 2) functional

capabilities of a sample of Navajo children attending Heardstart programs.

Study of selected diagnostic conditions. This study (Fleshman, 1983a) examined the prevalence of nine diagnostic conditions related to the occurrence of developmental disabilities. The number of children identified by condition are displayed by Figure 5. As shown, a total of 556 children aged 0-5 years are estimated to have one of the nine conditions. If having any of these conditions is taken as proof of a developmental disability, then the prevalence rate can be estimated at around 2.2%, based on an estimate of 25,000 children aged 0-5 years living in the Navajo Nation.

Figure 5: Number of Navajo Children Aged 0-5 Years Estimated to Have a Developmental Disability by Nine Diagnostic Conditions *

Diagnostic Condition	Reported or Estim/year **	Incidence/1,000 Live Births	Estimated Number with Dev Disability
Bacterial Meningitis	47.0	7.8/1000 at or below 18 months	54
Low Birth Weight	264.0	35/1000	85
Fetal Alcohol Syndrome	16.0	3.6/1000	85
Fetal Alcohol Effect	n/a	1.8/1000	40 (estim)
Hydrocephalus	3.0	0.7/1000	10
Myelomeningocele	0.8	0.2/1000	4
Down Syndrome	5.0	1.26/1000	30
Cleft Palate	8.0	2.15/1000	48
Severe Trauma including abuse	99.0	4/1000 under 6 yrs	200
		TOTAL	556

* Source: Fleshman, 1983a

** Note: "Expected" figures were based on previously completed surveys of Navajo children or other Native Americans.

While this study provides useful information regarding the estimated prevalence of certain diagnostic conditions, it leaves much room for further research, as is pointed out by its author. Certainly, other diagnostic categories aside from the nine studied are associated with the occurrence of disability and must also be taken into account. Moreover, as discussed earlier, studies of disability based on diagnostic criteria alone fail to consider the impact of the condition on daily functioning. Some children with targeted diagnoses may function quite normally, suggesting that they ought not be counted as having a "developmental disability."

Functional capabilities of children attending Headstart programs. This study (Fleshman, 1983b) was undertaken in 1981-82 and involved a sample of 463 children aged 3-5 years who attended Navajo Headstart programs. The number represented about 20% of all Headstart students. Children were given the Denver Disabilities Screening Test (Frankenburg & Dodds, 1967) as part of a larger effort involving the Dine' Center for Human Development and the John F. Kennedy Child Development Center at the University of Colorado. One study purpose was to assess the test's applicability to Navajo children, given that it had been used previously to test children of other cultural backgrounds.

As shown by Figure 6, 7.6 percent of the Navajo children tested scored in the "abnormal" range, suggesting that they have significant developmental delays that require specialized intervention services. Further, another 32.8% were considered to have a "questionable" functioning status, suggesting that they require close monitoring and specialized attention. Though one may argue that the DDST is a culturally biased measure, placing Navajo children at a disadvantage, the findings generated from this study support claims that the prevalence of "developmental disability" among Navajo children is well above estimates for children living in other parts of the country.

Figure 6: Test Results of 463 Navajo Children Given the DDST

DDST Test Results	Number of Children	Percent of the Total
Normal	273	59.0%
Questionable	152	32.8%
Abnormal	35	7.6%
Untestable	3	0.6%
TOTALS	463	100%

C. Prevalence Based on Diagnostic Criteria

Staff at the Gallup IHS offices have for some time been collecting information on children aged 0-5 years. Of special interest are those children with diagnostic conditions thought to be associated with the onset of a "developmental disability." A total of 633 Navajo children aged 0-5 years were identified in the IHS data set with "suspect" diagnoses.

Figure 7 (shown on the next page) displays these diagnostic conditions by the number of times each was assigned to a child and also displays an unduplicated count of the 633 children by one diagnostic category. As shown, the most frequently made diagnosis is "developmental delay." Children given this classification are considered to be delayed in at least one aspect of their development (e.g., motor, language, cognition) when compared to their age peers, yet have not been assigned a "traditional" medical diagnosis to explain such delay. The second most frequently noted classification is "multiple impairment." These children are listed as having more than one disabling condition. No effort was made by project staff to assign these children a primary condition, owing to an absence of needed medical expertise and first hand knowledge on each child.

Figure 7: 633 Children with Suspect Disabilities by Condition

DOCUMENTED CONDITION	NUMBER OF CHILDREN WITH LISTED CONDITION	TIMES CONDITION APPEARS WITH OTHER CONDITIONS	UNDUPLICATED COUNT OF CHILDREN BY CONDITION
ALBINISM	1		1
APNEA SPELLS	1		1
ARTHROGRYPOSIS	2		2
ASPHYSIA	5	4	1
BECKWITH SYNDROME	1		1
BRONCHOPULMONARY DYSPLASIA	1	1	0
BULBAR PARALYSIS	1	1	0
BULLOUS SKIN DISEASE	1		1
CEREBRAL VASCULAR ACCIDENT	1	1	0
CHILD NEGLECT	1		1
CHRONIC EAR INFECTIONS	3	3	0
CONGENITAL AMPUTEE	1		1
CONGENITAL ANOMALIES	18	9	9
CONGENITAL CLEFT LIP & PALATE	14	10	4
CONGENITAL DEFORMITY OF LIMB	1	1	0
CONGENITAL DISLOCATED HIP	12	3	9
CONGENITAL HEART DEFECT	13	12	1
CEREBRAL PALSY -ATONIC	3	3	0
CEREBRAL PALSY -SPASTIC DIPLEGIA	2	2	0
CEREBRAL PALSY -SPASTIC HEMIPLEGIA	18	14	4
CEREBRAL PALSY -SPASTIC QUADRAPLEGIA	13	10	3
CEREBRAL PALSY -SPASTIC TRIPLEGIA	1	1	0
CRANIOSYNOSTOSIS	3	2	1
DERMOTHOMPSON	1		1
DEVELOPMENTAL DELAY	212	90	122
DOWN SYNDROME	24		24
DYSMORPHIC	26	25	1
EMOTIONAL DISTURBANCE	1	1	0
ENCEPHALOPATHY	2	1	1
EPILEPSY	70	55	15
FAILURE TO THRIVE	46	25	21
FETAL ALCOHOL EFFECT	3	2	1
FETAL ALCOHOL SYNDROME	39		39
FAS/FAE SUSPECTED	22	15	7
FUCOSIDOSIS	1	1	0
GASTROENTERITIS	1		1
HEARING IMPAIRMENT	14	12	2
HOMONYMOUS HEMIANOPSIA	1	1	0
HORNER'S SYNDROME	1		1
HYDROCEPHALY	16	14	2
HYPERTONICITY	2		2
HYPOGLYCEMIA	1	1	0
HYPOPHOSPHATEMIA	1	1	0
HYPOTHERMIA	1	1	0
HYPOTONICITY	22	18	4
KYPHOSIS	1	1	0
MECONIUM ASPIRATION	2	1	1
MENTAL RETARDATION	15	14	1
METABOLIC DISORDERS	1		1
MICROCEPHALY	11	8	3
MOEBIUS SYNDROME	1	1	0
MOHR'S SYNDROME	1	1	0
MULTIPLE BIRTH TRAUMA	1	1	0
MYELOMENINGOCELE	4	2	2
NEUROFIBROMATOSIS	1		1
POLYDACTYLY	1	1	0
POST MATURE	2	1	1
PRADER WILLI SYNDROME	1		1
PREMATURITY	119	47	72
R/O SEPSIS	1		1
RESPIRATORY DISTRESS	25	15	10
SCOLIOSIS	2	1	1
SMALL FOR GESTATIONAL AGE	8	8	0
SPEECH/LANGUAGE DELAY	22	17	5
SPEECH PROBLEM	21	14	7
SPINAL CORD INJURY	1		1
S/P BURNS	4	2	2
S/P CARDIAC ARREST	2	1	1
S/P HEAD TRAUMA	6	5	1
S/P INTRAVENTRICULAR HEMORRHAG	1	1	0
S/P MENINGITIS	52	31	21
TORCH INFECTION	1	1	0
TURNER'S SYNDROME	2	2	0
VACTERL SYNDROME	1	1	0
VISION IMPAIRMENT	10	10	0
MULTIPLE IMPAIRMENTS			143
IMPAIRMENT SUSPECTED BUT STATUS UNKNOWN			73
TOTAL NUMBER OF CHILDREN *			633

* NOTE: THIS TOTAL REPRESENTS THOSE CHILDREN AGED 0-5 YEARS WITH DOCUMENTED OR SUSPECTED CONDITIONS OR IMPAIRMENTS. THE AGE COHORT IS KEYED TO THOSE BORN BETWEEN 2/27/82 AND 2/27/87.

Using more stringent diagnostic criteria to assess the presence of a "developmental disability," Figure 8 shows the number of children found to have either autism, cerebral palsy, epilepsy, mental retardation or developmental delays. The former four categories are used by several states, including Arizona, to assess disability. Curiously, no child noted in the IHS data set is listed as having autism.

Figure 8: Number of Children 0-5 Years with any of Five Disabilities

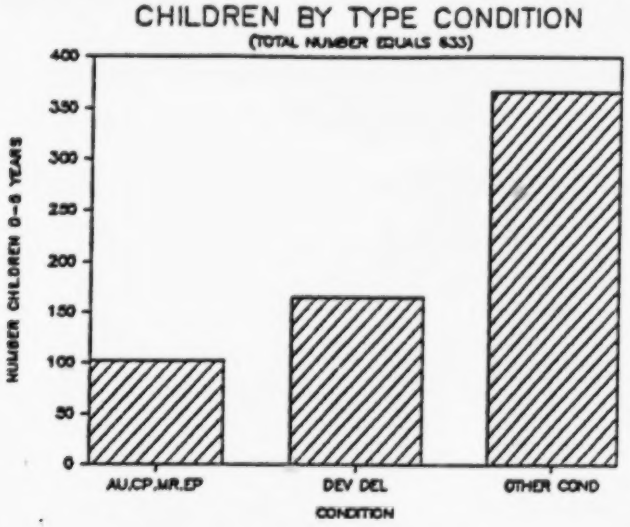
CONDITION	NUMBER OF CHILDREN	CUMULATIVE NUMBER OF CHILDREN
AUTISM	0	0
CEREBRAL PALSY	24	24
EPILEPSY	56	80
MENTAL RETARDATION	6	86
COMBINATION (AU,CP,EP,MR)	16	102
DEVELOPMENTAL DELAY	165	267

Figure 9 presents a comparison of the number of children assigned to three primary disabling categories: 1) autism, cerebral palsy, epilepsy and mental retardation, 2) developmental delay, and 3) other conditions. This figure demonstrates that significant numbers of children fall into categories (i.e., developmental delay, other conditions) that are excluded from traditionally used descriptors of developmental disability (i.e., autism, cerebral palsy, epilepsy, mental retardation).

Figure 10 displays relative prevalence rates key to the three primary categories noted above. The estimates are based on an estimate of 28,000 Navajo children aged 0-5 years living in the seven IHS areas. In the absence of firm figures documenting the number of Navajo children aged 0-5 years, the estimate of 28,000 children was calculated in four steps:

1. The Navajo population in 1986 was placed at 175,000 (Indian Health Service, Chart Series Book, April, 1985);

Figure 9: Number of Children Falling Into Three Primary Categories



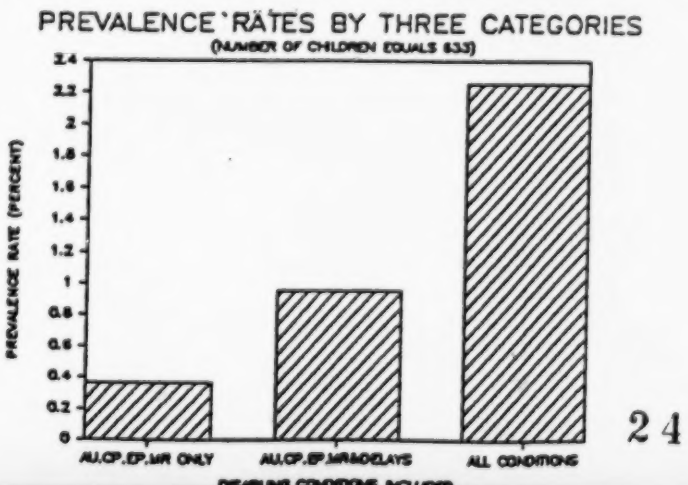
2. The number of Navajo children aged 0-14 years was placed at 45% of the population, based on findings emerging from the 1980 census (IHS Office of Planning and Development, 1980)

3. Simple multiplication (.45 * 175,000) yields an estimate of 78,750 Navajo aged 0-14 years.

4. Assuming an even distribution of children across the 14 year period, the number of children between 0-5 years (5/14 or 36%) is estimated at 28,350 children, rounded down to 28,000.

Project staff recognize that the above noted process is based on several assumptions that may not be entirely accurate. For instance, the rising birth rate on the Navajo Nation was not taken into account, perhaps resulting in a underestimate of the number of children aged 0-5 years. Yet without more precise information to draw from, such an estimate had to be used.

Figure 10: Prevalence Estimates Keyed to Three Primary Categories



As displayed by Figure 10, if diagnoses of autism, cerebral palsy, epilepsy and mental retardation are the only criteria used to determine the presence of a "developmental disability," the estimated prevalence rate is about 0.3%. When children with developmental delays are factored in, the prevalence rate climbs to nearly 1.0%. Finally, when all children with suspect diagnostic conditions are added in, the rate rises to 2.2%, coincidently the same figure estimated by Fleshman (1985a).

D. Prevalence Using Functional Criteria

In addition to information compiled on the diagnostic conditions of those children served, staff at the Gallup IHS have also begun to assess the functioning status of these children. This IHS data base contains information on 617 children in six of seven IHS areas (data regarding the Winslow area was not available) by age group (0-2 years; 3-5 years) and severity of the disabling condition (i.e., impact on the child's capacity to function).

Based on a scoring system designed by IHS staff, severity of the disabling condition was scored 1-6 as follows:

1: Near Normal Functioning	4: Moderate Functional Impairment
2: At Risk/Suspect	5: Severe Functional Impairment
3: Mild Functional Impairment	6: Profound Functional Impairment

Individual evaluations were based on review of the child's status by IHS staff in these six domains: health or medical condition, physical mobility, sensory acuity (i.e., hearing and sight), capacity to perform adaptive skills (e.g., eating, toileting), developmental progress, and socio-behavioral status. Figure 11 displays the criteria associated with each functioning level. Note that a score assigned to a particular child cannot be used to set a detailed habilitative plan because it offers only a rough estimate of the child's functioning level. When viewed in aggregate, however, such scores can provide an overall rough profile of the types of children under consideration.

Figure 11: Criteria Associated with Six Functioning Levels

1. **NORMAL or NEAR-NORMAL:** These children have no apparent disabling conditions.

2. **AT RISK/SUSPECT:** Though these children have no disabling conditions warranting great concern, they are not classified as "normal," due various slight abnormalities (e.g., premature by greater than 4 weeks, significantly small for gestational age, minor congenital anomalies, suspected sensory impairments, mild abnormality in muscle tone, respiratory distress, high risk maternal history, variable/more than normal health problems).

3. **MILD:** These children have documented disabling conditions, but their impairments are considered relatively mild (e.g., documented delays in reaching developmental milestones of less than 6 months from chronological age, mild sensory impairment, mild degree of hypotonicity, hypertonicity or flucuating muscle tone, mild degree of maladaptive behavior, minor/chronic health problems).

4. **MODERATE:** These children have documented disabling conditions that are considered relatively moderate (e.g., documented delays in reaching developmental milestones in excess of 6 months but less than 1 year from chronological age, presence of primative reflexes that interfere with movement, moderate degree of hypotonicity, hypertonicity or flucuating muscle tone, moderate degree of maladaptive behavior, functional use of limbs requires some form of support, moderate levels of sensory impairment, chronic/controlled health problems).

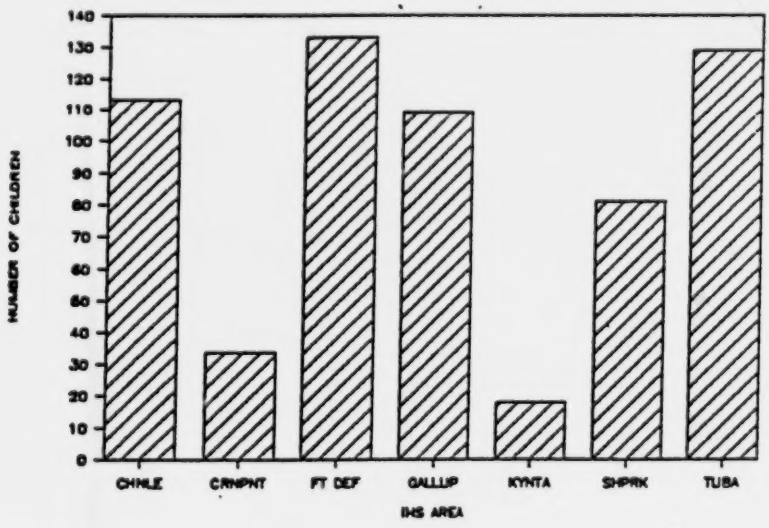
5. **SEVERE:** These children have documented disabling conditions that are considered relatively severe (e.g., documented delays in reaching developmental milestones from 12-18 months from chronological age, intellectual development considered to be 1/3 of that expected for chronological age, presence of primative reflexes that causing musculoskeletal deformity, severe degree of hypotonicity, hypertonicity or flucuating muscle tone, severe degree of maladaptive behavior, limited functional use of limbs, multiple/chronic health problems).

6. **PROFOUND:** These children have documented disabling conditions that are considered relatively profound (e.g., dominated by primitive brain stem developmental reflexes, multiple musculoskeletal deformities, intellectual development considered to be 1/4 of that expected for chronological age, totally dominated by abnormal muscle tone with little voluntary movement, severe problems with eating, no functional use of limbs, profound sensory impairment, totally incapacitated due to health problems).

What follows is a review of the information generated from analysis of this IHS data set. When examining these data, keep in mind that the figures may underestimate the actual prevalence of developmental disabilities. IHS staff warn that conditions in some IHS areas were not examined as thoroughly as in others, given staff shortages and time constraints.

Figure 12 displays the total number of children identified in each IHS area by severity of disability and shows that a total of 617 children were identified, not including the Winslow IHS Area. Of these 617, the greatest number of children with disabilities are found in the Fort Defiance (n=133), Gallup (n=109), and Chinle (n=113) IHS areas, while the fewest are found in Kayenta (n=18) and Crownpoint (n=34) areas.

Figure 12: 617 Children by IHS Area (Excluding the Winslow Area)



DISTRIBUTION OF DISABILITY BY REGION

IHS SERVICE AREA	NEAR NORM: SUSPECT	MILD DISABILITY	MODERATE DISABILITY	SEVERE DISABILITY	PROFOUND DISABILITY	TOTAL
CHINLE	51	33	21	3	5	113
CROWNPOINT	15	5	11	2	1	34
FT. DEFIANCE	75	26	14	4	14	133
GALLUP	62	27	13	2	5	109
KAYENTA	8	4	4	1	1	18
SHIPROCK	55	11	6	5	4	81
TUBA CITY	60	23	21	14	11	129
WINSLOW						0
TOTAL	326	129	91	31	41	617

Figure 13 depicts these children by IHS area as a percentage of the total number of children in the data set and offers a comparison to the percent of the Navajo population residing in each of the six IHS areas in 1980. Review of this figure suggests that the distribution of disability is not in proportion to the distribution of the overall population. This finding may hold some validity, but may also reflect an uneven approach to collecting data across IHS areas, as noted by IHS staff. Certainly, this finding warrants further attention involving closer inspection of children in IHS areas that appear under or over represented, though the number of children identified to date offers an ample data base from which to work.

Figure 13: Distribution of 617 Children in Comparison to the Population Distribution by IHS Area

COMPARISON OF POPULATION DISTRIBUTIONS BY IHS AREA

IHS SERVICE AREA	POPULATION (FY 1984)	PERCENT OF POP	# CHILDREN ALL	# CHILDREN 3-6	% OF TOTAL ALL	% OF TOTAL 3-6
CHINLE	22,691	14.06%	113	62	18.31%	20.46%
CROWNPOINT	12,523	7.76%	34	19	5.51%	6.27%
FT. DEFIANCE	22,824	14.15%	133	58	21.56%	19.14%
GALLUP	24,000	14.87%	109	47	17.67%	15.51%
KAYENTA	13,267	8.22%	18	10	2.92%	3.30%
SHIPROCK	35,225	21.83%	81	36	13.13%	11.88%
TUBA CITY	19,146	11.87%	129	71	20.91%	23.43%
WINSLOW	11,676	7.24%	??	??	??	??
TOTAL	161,352	100.00%	617	303	100.00%	100.00%

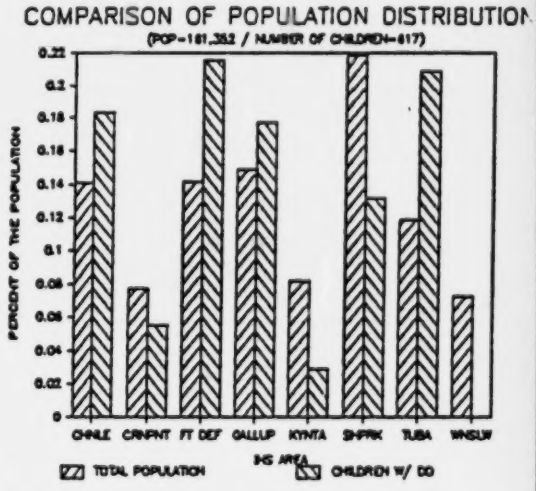


Figure 14 shows the number of children in the IHS data set by severity of their disability. Similarly, Figure 15 shows the cumulative number of children at each level of disability. As shown, the majority of children are considered "near normal" or simply "suspect," while relatively few have severe or profound disabilities.

Figure 14: Children by Severity of Their Disability

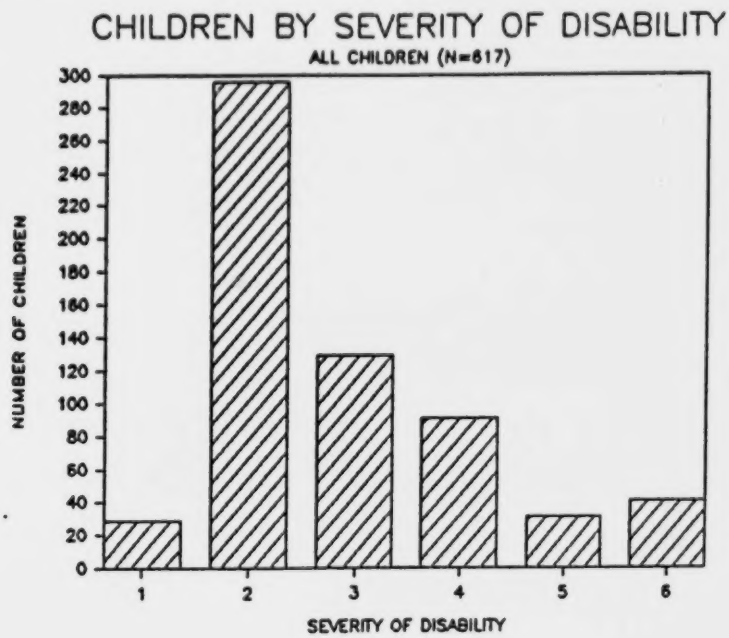


Figure 15: Cumulative Number of Children at Each Disability Level

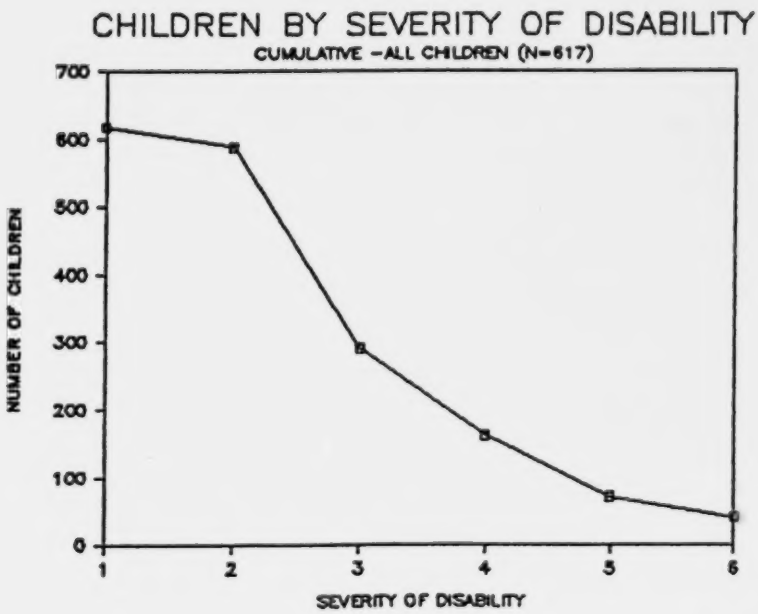


Figure 16 displays relative prevalence rates (excluding the Winslow area) that are based on an estimate of 26,000 Navajo children aged 0-5 years living in six of the seven IHS areas. As documented earlier the number of Navajo children 0-5 years is estimated at 28,350. Because the Winslow IHS area is excluded from the data set considered, however, children in this area must be substracted from the estimate. In 1980, the Winslow area accounted for 7% of the total population. Subtracting 7% from the estimate of 28,350 children yields an estimate of 26,366 children, rounded down to 26,000.

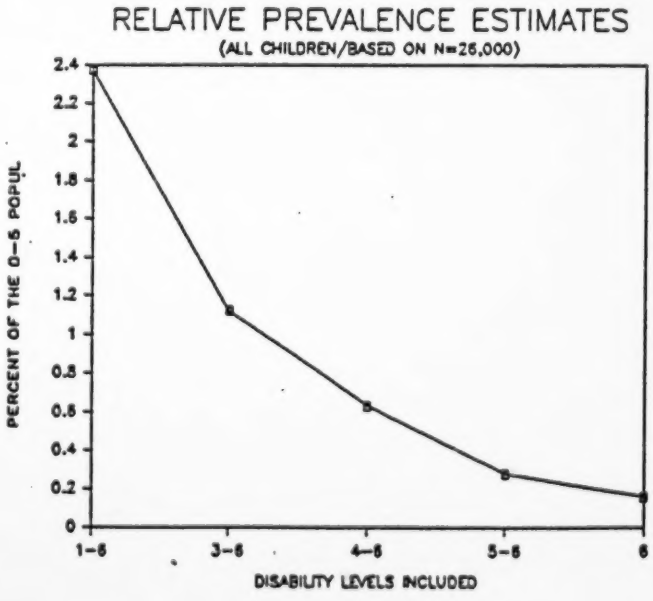
As suggested by Figure 15 and shown in Figure 16, the prevalence rate varies according to how one defines "developmental disability." If all children are included, even those with near normal functioning and those simply at risk, the rate is higher (2.37%) than if only children with the most severe disabilities are included.

Figure 16: Relative Prevalence Rates Based on Severity of Disability

RELATIVE PREVALENCE RATES

(EXCLUDING WINSLOW POPULATION ESTIMATE)
(BASED ON POP OF 26,000 CHILDREN AGED 0-5)

DISABILITY LEVELS	NUMBER OF CHILDREN	PERCENT OF 28,000
1,2,3,4,5,6	617	2.37%
3,4,5,6	292	1.12%
4,5,6	163	0.63%
5,6	72	0.28%
6	41	0.16%



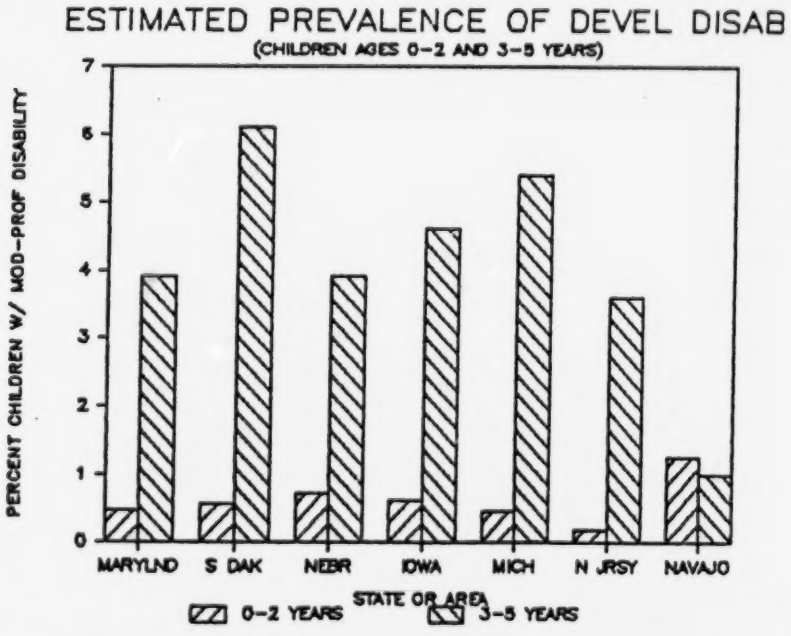
These estimated prevalence rates may seem low to some. However, as shown by Figure 17 review of data available from states offering early intervention services to children 0-2 aged years with moderate to profound disabilities

(i.e., Levels 3,4,5,6) reveals that the estimated rate, including all like children aged 0-2 years in the IHS data set, is higher among Navajo than in any of the other states.

In contrast, Figure 17 also presents similar data for children aged 3-5 years and shows that while prevalence rates rise sharply in other states when compared to the rates for children 0-2 years, the rate remains relatively stable in the Navajo Nation. In fact, it drops slightly.

The rise in other states is likely due to aggressive early intervention programs that identify children either as having substantial functional limitations or at risk of such limitations. In the Navajo Nation, however, early intervention programs are not a significant factor due to their few number, resulting in a failure to identify children who in these other states would likely be identified.

Figure 17: Comparison of Prevalence Estimates with Other States



* State estimates based on figures made available through implementation of PL 94-142 mandates to serve children aged 0-2. Children identified generally have at least moderate disabilities or delays.

* Estimates regarding Navajo were compiled based on data available through the Indian Health Service. Children identified have at least moderate delays or disabilities.

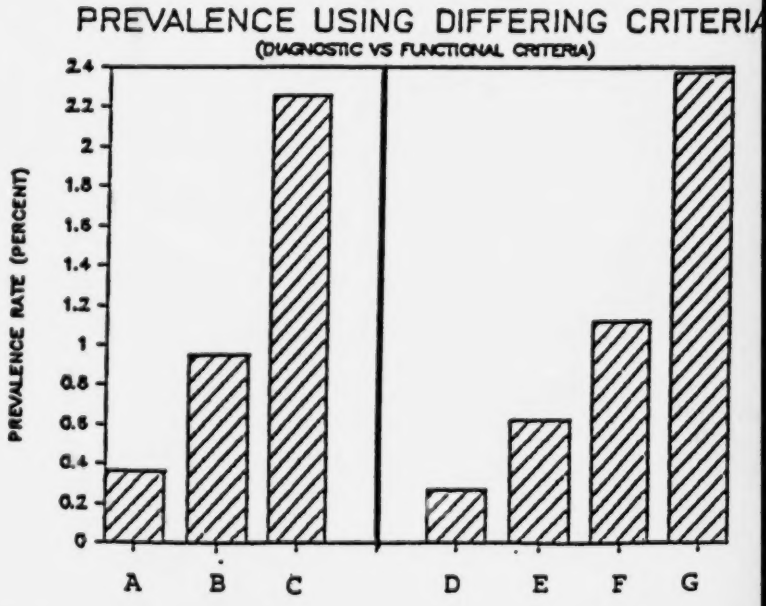
E. Comparison of Prevalence Rates Based on Differing Criteria

Rates pertaining to the prevalence of "developmental disabilty" vary in great part based on how the term is defined. Figure 18 displays a comparison of prevalence rates according to whether categorical (i.e., diagnostic) or functional definitions are used. The first three sets of criteria shown are diagnostic: A) autism, epilepsy, cerebral palsy, and mental retardation, B) autism, epilepsy, cerebral palsy, mental retardation, and developmental delays, and C) all conditions (See Figure 7). In contrast, the last four sets of criteria pertain to the child's functional status: D) functional levels 5 and 6, E) levels 4,5 and 6, F) levels 3,4,5 and 6, and G) all functional levels.

As shown, depending on the criteria employed, the prevalence rate ranges from less than 1% to about 2.3%, or from about 100 to 644 children. When reviewing these figures, however, it must be understood that they are based on IHS data sets that may not include all those Navajo children who may have a disability. Several children, especially those aged 3-5 years, have likely slipped past screening practices employed by IHS staff, resulting in an unavoidable underestimate of the number of children with disabilities.

Figure 18: Comparison of Prevalence Rates

Key	Criteria Used	Prevalence Rate	Number of Children
A	AU,CP,EP,MR	0.36%	102
B	AU,CP,EP,MR, & DEV DELAYS	0.95%	267
C	ALL CONDITIONS	2.26%	633
D	LEVELS 5 & 6	0.28%	72
E	LEVELS 4,5,6	0.63%	163
F	LEVELS 3,4,5,6	1.12%	292
G	ALL LEVELS	2.37%	617



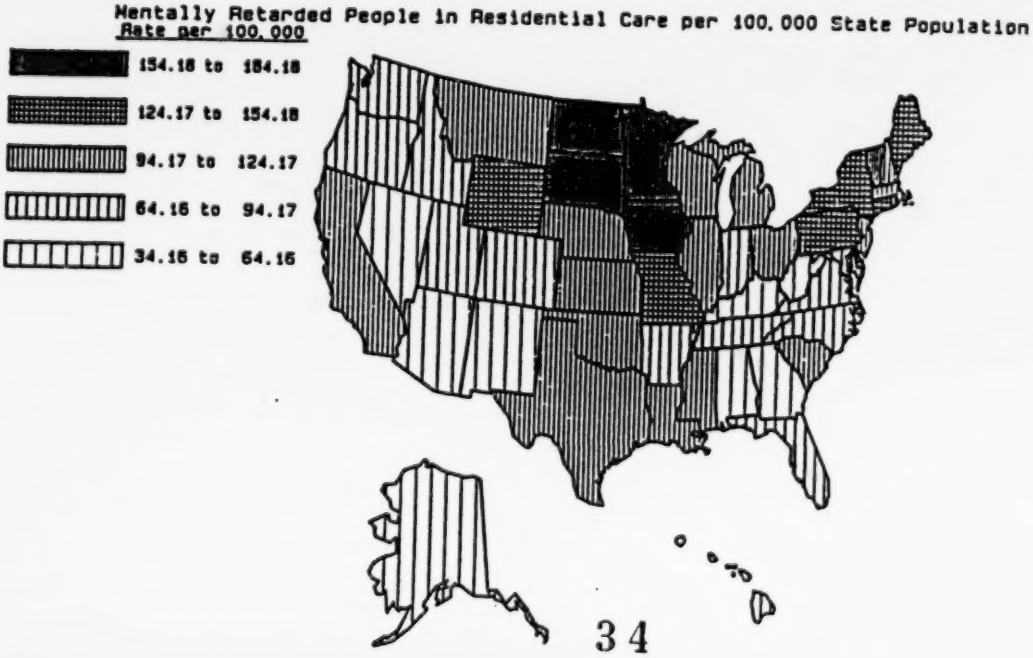
Additional discussion among concerned parties in the Navajo Nation is necessary to reach consensus over the best means to determine the presence of a "developmental disability." Such discussion is crucial since its outcome will, in great part, determine the approximate number and type of children who ought to be eligible for services, knowledge that is key to designing an effective community-based services system. Regardless of the outcome of future discussion, however, these preliminary estimates demonstrate that hundreds of young children with disabilities live in the Navajo Nation. Perhaps more important than computing a "precise" prevalence rate is assuring that these children and their families are receiving the services they require.

SECTION III: SERVICES REQUIRED BY CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

A. Background

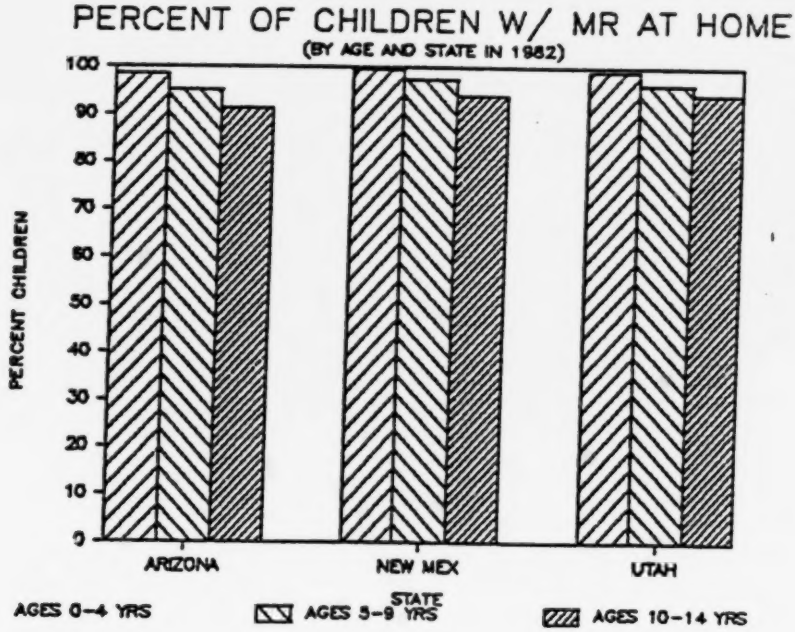
Most children with disabilities spend the early developmental part of their lives at home with their families. Researchers at the University of Minnesota (Hauber, Bruininks, Hill, Lakin & White, 1982) recently completed a national survey that reveals the frequency in which persons with mental retardation are placed into residences outside the family home (e.g., institutions, group homes, foster care, adoptive homes, nursing homes). Figure 19 shows that out-of-home placement rates vary from state to state, with northern midwestern states having the highest rates of out-of-home placement. In contrast, western states, including Arizona, New Mexico and Utah have relatively low rates. Overall, these survey results suggest that, on average, over 80% of those with mental retardation do not live in residences funded by the public sector. Rather, they are at home living with their families. These findings likely hold true for children with other types of disabilities as well (e.g., developmental delay, cerebral palsy).

Figure 19: Out-of Home Placement of Persons with Mental Retardation


Mentally Retarded People in Residential Care per 100,000 State Population
Rate per 100,000
154.18 to 184.18
124.17 to 154.18
94.17 to 124.17
64.16 to 94.17
34.16 to 64.16

Focusing on young children and on Arizona, New Mexico and Utah in particular, Figure 20 displays the percent of those with mental retardation thought to be at home by three age groups. The percent of those living at home decreases as their age increases. Yet this figure clearly demonstrates that the overwhelming majority (over 95%) of children with mental retardation aged 0-5 years are living with their families. Again, there is every reason to believe that these findings also hold true for children with other developmental disabilities. Given these circumstances, two key questions come to mind: 1) how can these children receive the services they require while they live at home? and 2) what must be done to enhance the familiy's capacity to provide home care?

Figure 20: Percent of Those with Mental Retardation Living at Home in Arizona, New Mexico and Utah by Three Age Groups



B. The Needs of Children with Developmental Disabilities

Irrespective of the definitional criteria used, children with developmental disabilities require special care due to physical and/or mental impairments that limit their capacity to perform a variety of life skills, or threaten such limitation. Review of the information presented earlier suggests that:

- "Developmental delay" is a frequent disability listed for many of those identified as having a significant disabling condition. In comparison to typical children of an equal age, these children are developing at a slower rate, and tend to fall behind in areas such as language, cognition, mobility, and motor development;
- Children with developmental disabilities often possess multiple disabling conditions; and
- Taken as a group, children classified as having a developmental disability have a great variety of disabling conditions and differ in the severity of their impairment.

Given these considerations, children with developmental disabilities can have extraordinary needs pertaining to their:

- Health status: Several types of disabling conditions require frequent monitoring of biological functions, requiring that caretakers be knowledgeable about the means for coping with medical emergencies;
- Health maintenance: Many health professionals are not trained to cope with extraordinary health needs of children with developmental disabilities. Consequently, many routine health maintenance tasks are greatly complicated. A child with a severe reverse tongue thrust and little voluntary muscle control may need to see a special dentist. Likewise, a child with down syndrome and a chronic heart condition may need to see a doctor who is familiar with such health conditions;
- Adaptive skills: Children with mental retardation have problems with learning. Likewise, children with developmental disabilities and normal intelligence may acquire skills at a reduced rate because of their physical condition. Regardless of the the nature of the problem, such children generally require increased opportunities for learning and can benefit greatly from specialized instructional assistance throughout life in a variety of settings (e.g., family home, intervention program);
- Socio-behavioral skills: Among children with developmental disabilities, the inability to learn and grasp concepts quickly, diminished ability to communicate or the frustrations of having a disability can result in maladaptive behavior. Eliminating such behavior can require extraordinary effort from parents and may necessitate consultation with a behavioral specialist. In addition, even if such needs do not evolve, children with disabilities may require counseling to promote development of a healthy self concept; and

- Other Developmental Skills: Many children with developmental disabilities require specialized treatment such as communication training or physical therapy. In addition, they may require a variety of personal or environmental prosthetics (e.g., adaptations to the home, eyeglasses, hearing aids, wheelchairs).

In addition to the several needs described above, it must be understood that the needs of any child with developmental disabilities will change over time as he or she progresses from one developmental plateau to the next (Konanc & Warren, 1984; Suelzle & Kennan, 1981). Consequently, service agencies must offer services capable of flexing with the changing needs of the child, coordinating efficiently with other agencies or professionals when needed.

C. The Needs of Families

Providing home care to a family member with disabilities can be a challenging task, taxing a family's emotional and financial resources. For many families the initial recognition that a disability exists presents an immediate crisis that evolves into a life crisis. Several of the problems families can experience include:

- Natural reactions to the discovery that a family member has a developmental disability, including a sense of shock or numbness, denial, grief, shame, guilt and depression (Fortier & Wanlass, 1984; English & Olson, 1978);
- Chronic stress (Wikler, 1983; Kazak & Marvin, 1984; Beckman-Bell, 1981);
- Dramatic changes in lifestyle, often affecting past established social relationships within the family, and with friends or extended family (Longo & Bond, 1984; English & Olson, 1978);
- Financial costs or lost opportunities for employment or education (Turnbull, Brotherson & Summers, 1985; Gliedman & Roth, 1980);
- Extraordinary time demands involved in providing personal care to the family member with disabilities (Apolloni & Triest, 1983);
- Difficulty with physical management (e.g., ambulation, lifting, carrying) and in handling socially disruptive or maladaptive behavior (Tausig, 1985; McAndrew, 1976);
- Difficulty in undertaking normal family routines such as shopping and house cleaning or in finding ample opportunity for recreation (Bayley, 1973; Lonsdale, 1978; McAndrew, 1976); and
- Lack of the skills needed to cope with the potential medical emergencies and/or to teach necessary adaptive skills (Turnbull, et al, 1985).

Recent thought suggests that a family's capacity for providing home care can vary dependent on the severity of the family member's disability, family characteristics and beliefs, and the availability of community support services. Though not all families experience serious problems, all are "at risk" because they are more likely to have difficulties than families without members with disabilities.

Additionally, two other factors must be considered. First, as parents grow older their capacity to provide care changes, often spurring need for additional in-home support or placement of their child with disabilities into an alternative residence. Second, in addition to meeting daily life requirements, parents must eventually give thought to how the needs of their family member with disabilities can be appropriately met after they can no longer provide direct care. In fact, recent studies report that parents begin worrying about their child's future very early in their child's life (Agosta, Bass & Spence, 1986).

To assess the particular circumstances of Navajo families, project staff convened an informal family forum and conducted individual family interviews. Together, these activities involved 29 family members who are providing care at home to children with disabilities aged under five years. Eight parents have children who are receiving "minimal" services in the Kayenta area, 12 have children enrolled in the day programs offered by the St. Michaels Association for Special Education in St. Michaels, Arizona, and the remaining nine have children enrolled in Headstart services or have been referred to this program.

Consistent with family preferences identified elsewhere (See pages 26-27), the great majority of these family participants are not planning to seek long term out-of-home placements in the near future, but plan to continue to provide care at home despite the challenges such care presents. It should be noted that the two parents who are making plans for an alternative placement are

doing so with good reason; reasons that may well have been countered given the provision of strong family support services. In one case, the primary caregiver (an aunt) feels that providing home care disrupts family life too much and more time is needed to devote to other family members, while in the second case the parent felt compelled to seek an out-of-home placement to obtain needed services for a deaf child.

Though a wide range of needs were identified by family participants, discussion focused heavily on these seven areas:

- Housing. The overwhelming majority of families expressed a need for improved housing, especially housing with running water and electricity. The absence of these utilities frustrate families trying to provide the best home care, especially those seeking to follow medical advice regarding their children's health care. For example, some parents are unable to give their child frequent hot water baths for therapeutic purposes because water must be hauled from as far away as 40 miles!

- Mutual support groups. The majority of families wanted to interact with other caregiving families more often to discuss mutual concerns and otherwise assist eachother. Some parents suggested that members of such support groups could help educate others regarding disability and its prevention;

- Medical and habilitative services. Most family participants expressed a need for medical insurance that would cover more of the cost of medical care for their child with disabilities. Two parents indicated that the Indian Health Service is not obligated to provide "specialized" medical treatment, and that certain special services are only available through contract based on the availability of funding and IHS approval. Likewise, the majority of families identified a need for doctors and dentists who understand how to care for children with disabilities. Finally, the majority felt that their children are in need of developmental interventions and specialized therapies, such as physical and speech therapy;

- Temporary or part-time help (respite care). Many parents indicated that they simply need a break from providing home care every now and again or to make it possible for the primary caregiver to go to work. One of the working parents commented that while center-based day care services are available in her community, they are not accessible to her because of high user fees and restrictions placed on the age of the child that will be served. Often, day care centers will not accept infants or toddlers. Additionally, parents noted that temporary help is needed in times of illness, when other children require parental time, during family emergencies, or to attend communal functions like tribal ceremonies;

- Information and referral. The majority of family participants indicated a need for a great range of information, including information on: 1)

the nature of their child's disabling condition, 2) how to care for or educate their child most effectively, 3) how to obtain needed services, 4) how to deal with behavior problems, and 5) the future financial welfare of their child. In fact, like parents across the country, these parents were especially worried about what the future holds for their child;

- Recreational opportunity for their child. Nearly all parents expressed a need for opportunities for their child to recreate. Many children with disabilities are not provided such opportunity at an early age. Not surprisingly, these children fail to develop needed social skills, skills they will need throughout life if they are to find their place within their community; and

- Transportation services. The majority of parents indicated that they have difficulty finding means to transport their child to needed services. Obviously, even if a full array of services were available, families without transportation would be unable to access these services.

Complementing the above stated needs were the many individual comments made by family participants. Their comments touched on a wide range of issues and sometimes reflected differing opinion. A sampling of such comments is as follows:

- "The public school says that it will serve my child next year. I don't think the public school is appropriate for him because he requires special attention and treatment. No one at the school will have the time to feed him, or to carry him to the bathroom when needed;"

- "If services were available locally, perhaps we could obtain training as aides and assist with therapy;"

- "We need an overall policy for handicapped children and their families in the Navajo Nation;"

- "Riding on the school bus with normal children is not appropriate because my child cannot get on or move very fast. He will get ridiculed and teased by the children. As a result, he will eventually lose interest and drop out of school. If the public school wants to mainstream our children, then it should at least provide an aide to accompany our children in the bus so that they will not get hurt;"

- "Tribal leaders and school board members need more education about the needs of handicapped children;"

- "I had to turn down a higher paying job offer because there were no services available for my child at the proposed job site. Parents are tied down to places where their child can receive needed services;" and

- "The existing child find programs are not effective. There are alot of handicapped children who are not in school but who are at home without any services."

In summary, although many of the family participants expressed feelings of frustration, they also were optimistic that services in the Navajo Nation will soon be improved. This hope was eloquently expressed by one parent:

> "If we could just keep mindful of the teachings of our grandparents to consider handicapped children as special persons like our holy people, then the path to peaceful minds for our children and ourselves will be found."

D. Overall Needs of Children and Families

Given the needs of children with developmental disabilities and the several challenges that families may face, Figure 21 displays many of the services that families and their members with disabilities could require. In addition to those services listed all families and children could benefit from a "casemanager" or "case consultant" to assist with determining what services are needed and with gaining access to such services. This list was distilled from a review of existing family support programs operating around the country and the results of the Navajo family forum and interviews, and suggests that in addition to the direct care services required by the family member with disabilities the family also needs support services to enhance its capacity to provide care at home.

These potential service needs are not ranked in order of importance. Each family has a unique cluster of needs and would place a different value on each service depending on their immediate circumstances. Additionally, many families may have needs that do not appear on the above list. This last point is especially important, given that Navajo cultural beliefs may well influence the types of services that should be made available.

Figure 21: List of Services Required by Children with Developmental Disabilities and Their Families.

Home-Based Services Centered Around the Person with Disabilities	Services Centered Around Family Members
diagnosis and assessment	information and referral
educational/therapeutic services	temporary relief/respite
medical or dental services	family counseling
home health care	parent/sibling education
traditional healing practices	day care
special clothing	housekeepers
special diets	cash assistance
transportation	guidance for planning the future
adaptive equipment	parent mutual support groups
housing adaptations	adequate housing
recreational services	

E. Present Status of Services

Few would agree that the present array of services available to Navajo children and their families is sufficient. Though the work of professionals throughout the Navajo Nation is well appreciated, existing programs do not reach all those who require services nor do they offer the wide array of services needed.

In this regard, review of a resource directory (NAIHS Area Rehabilitation Office, 1986) for services in the Navajo area is instructive. The directory may not list all those programs offering services in the area, but is the most complete compendium available. It provides information on services available across the entire Navajo area, specific to each IHS area, and for residents of Arizona and New Mexico. Information offered includes: 1) program name, address, phone number and contact person, 2) eligibility criteria, 3) services offered, and 4) other relevant information.

Review of this directory suggests the following observations:

- Access to services: Available services are not easily accessed by numerous families on behalf of their children nor are services equally distributed across the Navajo area. To a great extent, this issue is

related to the paucity of available programs generally and the rural character of the land. Though there are innovative programs available, these programs are few and cannot serve all those in need. Thus families in one part of the Navajo Nation often cannot gain access to services other families living elsewhere receive regularly. Likewise, where a needed service is available, families often must travel substantial distances to the program, reducing the liklihood of their participation. This issue, however, is not equally apparent across all types of programs. For instance, essential health care is typically available and accessible. However, other needed services such as language therapy and home-based parent education are not always available or easily accessed;

- Program eligibility: Though health care is available to all, needed habilitative or developmental services are not. Many instructional programs restrict the age of those admitted to five years or older, while others focus on children aged 3-5 years. Relatively few programs are designed for children aged 0-2 years. Additionally, some programs place restrictions on the types of children served (e.g., multiple impairments, developmental disabilities);

- Family support services: Very few services designed to support the family or enhance its capacity to provide home care are available. Services appear to focus nearly exclusively on the child with disabilities; and

- Service context: Though there are exceptions, available services are typically "center-based." That is, service recipients must go to the program, rather than be visited in their home by a program professional. Again, this approach may be in some part necessary due to the rural environment and overall lack of services, but as services grow in number means must be found to provide certain services in the family home.

Following up on these initial impressions, project staff undertook a survey of agencies offering services to children with disabilities aged 0-5 years. The purpose of this survey was to enhance our understanding of 1) the number and type of children served, and 2) the key issues facing service providers. Six service agencies participated in the survey, including:

1. Gallup McKinley County Public Schools (Educational Developmental Center)
2. Kayenta Early Intervention Services
3. Navajo Headstart, Division of Navajo Child Development (Crownpoint, Chinle, Tuba City, and Shiprock Agencies only)
4. New Horizons Early Childhood Program
5. St. Michael's Association for Special Education
6. Tuba City Pulic Schools

Children served. Figure 22 shows that 382 children with disabilities are served by the six reporting agencies. As shown, very few children aged 0-2 years are served in the Navajo Nation. Given data reported previously (See

pages 20 - 25), it appears that numerous children aged 0-2 years are not receiving the habilitative services they may need. In contrast, once children reach age three, many more are served.

Figure 22: Number of Children Served by Age Group

Program	Children 0-2 Years	Children 3-5 Years	Total
Gallup-McKinley	0	5	5
Kayenta Early Int.	3	10	13
Navajo Headstart	0	272	272*
New Horizons Prog.	15	20	35
St. Michael's Assn.	9	26	35
Tuba City Pub. Sch.	0	22	22
Totals	27	355	382

* Note: Because information could not be obtained in time from all Headstart agencies, figures do not count all those children served by Navajo Headstart. Headstart serves about 358 children with disabilities.

Respondents were also asked to classify the children they serve according to the six point rating system used in the IHS data set (See page 18). Figure 23 shows the distribution of the 382 children by functioning level. As expected few of those served have severe/profound disabilities, while most were assigned to the moderate/mild disability levels.

Figure 23: Functioning Levels of the Children Served

	Disability Level						
	Near Normal					Profound	
Program	1	2	3	4	5	6	Total
Gallup-McKinley	0	1	0	0	3	1	5
Kayenta Earl Int	0	2	5	3	2	1	13
Navajo Headstart	40	96	22	69	39	6	272*
New Horizons Prog	0	2	5	17	9	2	35
St. Michaels Assn	0	0	18	9	5	3	35
Tuba City Pub Sch	0	0	0	12	6	4	22
Totals	40	101	50	110	64	17	382

* Note: Because information could not be obtained in time from all Headstart agencies, figures do not count all those children served by Navajo Headstart. Headstart serves about 358 children with disabilities.

Key issues raised by survey respondents. Though a wide range of issues were raised, respondents most often and with greatest vigor cited these two: a lack of needed funding, and the lack of appropriate numbers of qualified staff. Although an absence of needed funds is noted frequently by agency managers and others as a barrier to program improvement and expansion, the availability of adequate funding is likewise not perceived as the only solution to existing service problems. More efficient use of existing resources (Note 1) may help correct current deficiencies. In addition, more could be done to encourage the use of natural support systems such as the extended family and friends. In this regard, advocacy groups (e.g., Dine Association for Handicapped Citizens) could play a significant role.

Improvements in resource coordination notwithstanding, there is an obvious need for finding additional sources of revenue. Recently passed federal legislation, The Early Intervention Act of 1986, Public Law 99-457 (see Appendix A), regarding the provision of early intervention services to children aged 0-5 years bears close watching. This legislation includes allocations to fund such services, but requires that each state devise its own plan for how targeted children will be identified and served.

NOTE 1: Existing resources include, but are not limited to:

- Bureau of Indian Affairs;
- Indian Health Services;
- Navajo Head Start;
- Navajo Division of Social Welfare;
- Navajo Council on the Handicapped;
- private interests (e.g., Save the Children Federation);
- state sponsored habilitation programs (e.g., education, community services);
- grant programs (e.g., those sponsored by state developmental disabilities planning councils); and
- institutions of higher education (e.g., Navajo Community College, the Native American Rehabilitation Research and Training Centers in located in Flagstaff and Tucson, Arizona).

The new law offers hope for improved services for children with disabilities. Additionally, the funds recently placed in trust on behalf of Navajo persons with disabilities (about 7 million dollars) by the Navajo Tribal Council may prove to be of great help (see Appendix B). Though plans have not yet been set with regard to how the interest earned from this investment will be spent, there is an indication that a portion will be allocated to enhance the present service array for young children with disabilities and their families.

The second major issue raised by survey respondents pertains to staffing. With regard to recruiting new direct care staff, four complaints were frequently made:

- It is hard to find staff experienced with developmental disabilities;
- It is hard to find staff experienced with young children;
- It is hard to find staff trained in specialized therapies; and
- It is hard to find a sufficient number of applicants, especially those who speak Navajo.

Finding and retaining competent staff are crucial to the success of any service system. As the Navajo Nation moves to provide services to young children and their families, care must be taken to nurture the development of a competent pool of labor from which to draw. Simply allocating dollars to the provision of direct services will not suffice. Instead, means must also be employed to attract workers to the human services field and to offer them the training they will need to provide services of the highest quality. As these ends are achieved, services will be improved and could be systematically expanded.

SECTION IV: RECOMMENDING POLICY AND PRACTICE

A. Background and Conceptual Framework

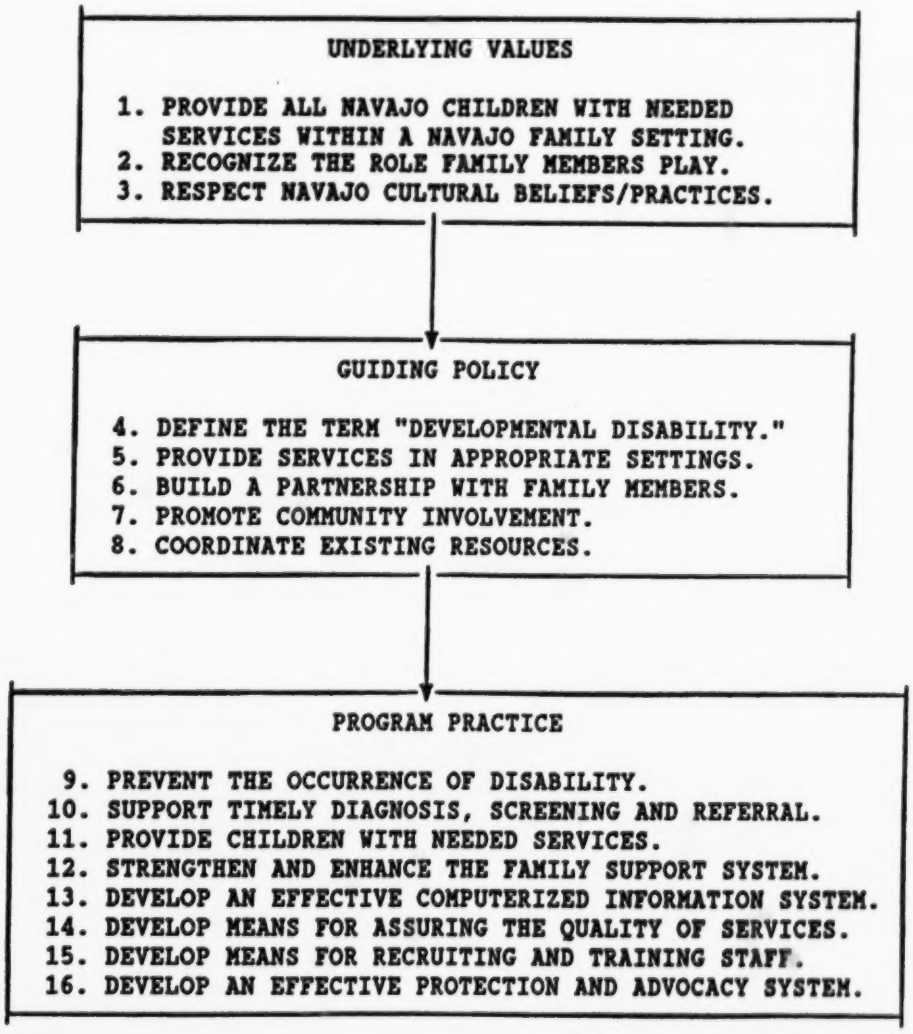
In November of 1986, the Navajo Tribal Chairman, Peterson Zah, appointed a Blue Ribbon Panel on Childhood Disability to examine means for improving services for children in the Navajo Nation. The members of this panel, listed on the face page of this report, represented numerous interests, including those of parents, health and habilitative professionals, advocates and policymakers. The panel met five times to participate in day long working sessions to: 1) consider information collected through other project activities, 2) discuss conceptual and logistical issues related to service delivery, and 3) reach consensus over what could be done to improve services for children with disabilities in the Navajo Nation. Though discussion was sometimes lively in face of conflicting opinion, it was always stimulating and filled with hope for the future.

The 16 recommendations emerging from the work of the panel reflect a variety of concerns and ideas for improving the Navajo Nation's current response to childhood disability. Given the range and mass of information considered, a conceptual framework was developed to ease review of the panel's work and to structure future discussion. This framework involves three major components: underlying values, guiding policy, and program practice. Figure 24 displays this conceptual framework and presents each of the 16 recommendations in abbreviated form under the most appropriate heading. Additionally, each recommendation is presented below under one of the three areas noted above.

B. Underlying Values

To implement a coherent service system that is maximally responsive to the needs of children with disabilities, thought must be given to the underlying values the system must personify. Three fundamental values pertain to the

Figure 24: Conceptual Framework Used to Present the Findings of the Chairman's Blue Ribbon Panel


UNDERLYING VALUES
1. PROVIDE ALL NAVAJO CHILDREN WITH NEEDED SERVICES WITHIN A NAVAJO FAMILY SETTING.
2. RECOGNIZE THE ROLE FAMILY MEMBERS PLAY.
3. RESPECT NAVAJO CULTURAL BELIEFS/PRACTICES.
GUIDING POLICY
4. DEFINE THE TERM "DEVELOPMENTAL DISABILITY."
5. PROVIDE SERVICES IN APPROPRIATE SETTINGS.
6. BUILD A PARTNERSHIP WITH FAMILY MEMBERS.
7. PROMOTE COMMUNITY INVOLVEMENT.
8. COORDINATE EXISTING RESOURCES.
PROGRAM PRACTICE
9. PREVENT THE OCCURRENCE OF DISABILITY.
10. SUPPORT TIMELY DIAGNOSIS, SCREENING AND REFERRAL.
11. PROVIDE CHILDREN WITH NEEDED SERVICES.
12. STRENGTHEN AND ENHANCE THE FAMILY SUPPORT SYSTEM.
13. DEVELOP AN EFFECTIVE COMPUTERIZED INFORMATION SYSTEM.
14. DEVELOP MEANS FOR ASSURING THE QUALITY OF SERVICES.
15. DEVELOP MEANS FOR RECRUITING AND TRAINING STAFF.
16. DEVELOP AN EFFECTIVE PROTECTION AND ADVOCACY SYSTEM.

children targeted for services, their families, and the community where they live. Three value based recommendations are offered.

1. All children, regardless of disability, have the right to receive services in a dignified and respectful manner in a Navajo family setting.

The design of any service system for children with disabilities must be premised on this fundamental value. Too often our response to disability has failed to take this value to heart, resulting in policy that encourages out-of-home placement or favors treatment in settings away from the family. By embracing this value, any response to disability must begin with policy and practice that is designed to assure that children grow up in a family setting.

Panel members recognize that some children with disabilities have conditions severe enough to warrant placement in specialty care settings and that some families may not be capable of providing the level of care needed. In such cases, residential placement away from the family home may be necessary. In keeping with the spirit personified by this value, however, any alternative placement ought to resemble a "Navajo family setting," to the extent feasible (e.g., placement with another family, small community-based home). Placement in congregate facilities, typically segregated from life's mainstream, ought to be avoided.

2. The role families play in providing home care must be recognized and nurtured.

As suggested by Figures 19 and 20, most children with disabilities spend the early developmental stages of their lives at home with their families. The role families play in providing care at home, however, is too often overlooked by policymakers who focus instead on providing the direct services required by children.

At the core of any effort to promote care within family settings must be a commitment to support and enhance the efforts of those family members who provide home care. Because in Navajo society life revolves around the family, the role that this institution plays in Navajo culture cannot be overemphasized. Consequently, policy and practice regarding children with disabilities must build on this longstanding tradition, involving families in planning and in service provision. Taking into consideration the special needs of children with disabilities and their families, support systems, furthermore, must be designed in ways that:

- recognize the family's underlying commitment to care for their family member with a disability;
- embrace practices that promote, not discourage, increased family independence from the formal service system; and
- take seriously the view of the family with regard to how services should be designed and rendered.

When these values are used to guide program design, the family support system, while based on the aggregated need of all families, is ultimately accountable to each individual family. As such, it empowers families on two levels:

- Systems level: Family members have significant input into the substance, administration and planning of services; and
- Family level: Family members have some control over the services they receive. Flexible multiple service options must be available and family members must have some say over the selection of services.

Some professionals warn that many family members are incapable of accepting an empowered role or want to be more dependent on outside direction. However, the absence of needed skills among some or the reluctance of others does not justify the substitution of professional judgement in all cases. To do so fosters dependence on professionals and discounts the potential of family members for making competent service related decisions.

Instead, service models must be founded on the assumption that all family members are potentially capable and willing to make responsible decisions; Families want the best for their members with disabilities. Given this presumption, the challenge for service planners is to establish partnerships among families and professionals that empower family members to the maximum feasible extent.

Of course, there are limits to the emotional, physical and financial resources of parents and their expertise. When first confronted with the advent of disability, many family members will have little understanding of what overall needs they will have. Moreover, even as time passes, some families will be unable or unwilling to accept an empowered role. The long term goal of the system, however, must be to equip family members, and eventually persons with developmental disabilities themselves, to provide and/or obtain competent care, not to ensnare them in bureaucratic mazes and to make them dependent on professional judgements.

3. The longstanding cultural beliefs and practices dominant within the Navajo community must be respected.

Services to persons with disabilities are universal acts of goodness. They are perceived as such by Navajo people. Like all other societies, however, Navajo perceptions of and approaches to serving persons with disabilities are unique. An understanding of the differences between the Navajo culture and other cultures underlies the basis of cultural sensitivity in the provision of services to Navajo with disabilities.

Services to Navajo with disabilities encompass a range of activities and levels of talent, the former including diagnosis and evaluation, therapeutic intervention, counseling and education, and Navajo traditional healing practices, and the latter, professional, ancillary, advocacy personnel, families and extended families, a bureaucratic system (Tribal government or organization), and Medicine Men.

In their pursuit of serving persons with disabilities, Navajo people are subjected to external forces and alien value systems. These become destabilizing forces, threatening the harmony of the Navajo culture and society. Such forces may be tempered, hence services made more culturally sensitive and relevant if they: 1) are made to fit logically into the Navajo societal order or set of behaviors, 2) are harmonious with the values embraced by the Navajo culture, and 3) present the least threat to the integrity of the Navajo society and culture, particularly its value system.

Cultural sensitivity to Navajo with disabilities above all takes into consideration the differences between "baadahaz a" and "bich i anahoot i," Navajo society's concepts of affliction of the mind, and of "binitsikees baadahaz a," harmony expressed as health, beauty and happiness.

C. Guiding Policy

Driven by these values, policy may be set to describe the target population, what must be accomplished, and how stated objectives will be achieved. In this regard, five recommendations were made.

4. Reach consensus over the definition of the term "developmental disability."

Key to the design of systematic planning strategies regarding childhood disability is a common definition of "developmental disability." As described earlier (See pages 4-25), defining this term requires that numerous complex issues be considered. Not surprisingly, due to the contrasting approaches taken to define the term, definitions vary across the country. Additionally, the Navajo Nation must cope with a unique problem: the overlapping juristictions of Arizona, New Mexico and Utah. Each state uses its own definition, and none are identical to the federal definition. Moreover, none necessarily reflect Navajo beliefs regarding disability. These circumstances create confusion within the planning process that ought to be corrected.

Toward that end, panel members urgently recommend that policy makers from the three relevant states and the Navajo Nation meet to reach agreement on a definition of "developental disability" that, at the very least, pertains to all residents of overlapping juristictional areas (i.e., the Navajo Nation), and reflects Navajo cultural values.

5. Services must be provided in the most appropriate living and learning environment, encouraging normalization of life, individualization of care, and a decent quality of life.

Every person, regardless of his/her physical or mental condition, is different, responding uniquely to seemingly similar circumstances, and having varying preferences and potential for success. Despite these differences, however, all persons are entitled to live their unique lives within society's mainstream, and to avail themselves the opportunity to reach their maximum

potential. Toward this end, panel members agreed that services ought to be designed in accordance with the following principles:

- Normalization of life. Children with disabilities should be encouraged to reach their optimal potential, functioning within the limits of their disabling condition yet stretching these limits through well designed treatment. Moreover, wherever possible children with disabilities must be served in settings frequented by their normal aged peers. Program approaches that segregate children on the basis of disability must be avoided in favor of practice that encourages integration. For instance, when offering day care, efforts must be made to equip existing day care programs to serve children with disabilities, rather than developing a segregated day care facility;

- Individualization of care. All children with disabilities should be evaluated individually with short and long term habilitative plans designed specifically for each child. Such plans shall articulate discrete program objectives spanning all the childs needs (e.g., health, developmental) as well as needs pertaining to family members who provide home care. Additionally, these plans shall designate responsibilities for providing needed services as appropriate; and

- Quality of life. All children, including those with disabilities, require love, nourishment, and other life essentials. When treated nondifferentially, children with disabilities can be guaranteed a quality of life equal to that experienced by other children living in the Navajo Nation.

6. Build a partnership with families to guide program design and delivery.

At the core of any effort to support children in their homes must be a driving set of principles that takes seriously the role that families play. Four such principles that could be used to guide policy include:

- Families are responsible caregivers and the family environment (the homes) is the preferred residential setting for children with disabilities;

- Families must participate in decisions regarding the nature of their service needs and in the selection of services;

- Family support programs must be flexible and possess the potential to adapt to individual family needs; and

- Services must promote and strengthen the role of existing informal support networks, including extended family members and neighbors, to complement families' efforts and those services offered through the public sector.

More than simply suggesting that professionals "consult" family members about the services their children need, these principles assert that family members

must be made a key part of the decisionmaking process. Additionally, these principles imply that services must also be made available to family members to support and enhance their efforts. Wherever possible the services provided ought to take full advantage of the naturally existing helping networks already available.

7. Implement means for promoting community awareness and involvement.

Community involvement and awareness must be encouraged through an active program of open and honest communication with the public, and by providing opportunity for people to participate in the delivery of services. Overall, the underlying purpose of this recommendation is to heighten community awareness regarding the needs of children with disabilities and to stimulate social action in their behalf.

To help achieve these ends, a systematic educational campaign may be helpful. Such a campaign may involve the distribution of brochures, fact sheets or newsletters, favorable publicity through newspapers, radio or television, or personal presentations at club meetings or community forums. The effectiveness of these approaches, however, is open to question. If used without systematic intent they seldom foster significant long-term change in community attitudes or behaviors. To make the greatest use of these practices, concerned parties should consider carefully the goals of any public awareness campaign, focusing on key issues and audiences whenever possible.

More important for the long-term are activities that <u>involve</u> persons in the delivery of care. First hand experience teaches, reinforces, and promotes development of enduring friendships. In this regard, the development of respite care programs that employ extended families or neighbors is key to the success of the effort. Similarly, recreational opportunities that engage community volunteers can also promote community goodwill and awareness. Though much more can still be done, some Navajo programs have already discovered the

benefits of this approach through their use of high school and college students as aides after school hours or during summer months.

8. Existing resources must be well coordinated to make maximum use of existing resources.

While all panel members agreed that the paucity of services was in great part due to an absence of needed funds, they were equally concerned that more could be done to make use of existing resources. Numerous instances where coordination among existing agencies could be improved were cited by panel members. Crucial to developing an efficient array of services will be a commitment of resouces and resolve among policy makers to identify precise areas of miscommunication and uncoordinated practice, and to deploy means for their correction.

D. Program Practice: Direct Services

The primary objective of the Navajo Nation's response to childhood disability is to assure that children with disabilities and their families receive those services they require. When delivering services two issues must be considered: a) the direct services received by children with disabilities and their families, and b) the administrative supports that must be in place to assure that direct services are of the highest quality. Panel members offer four recommendations pertaining to direct services.

9. Relevant agencies must work together to prevent the occurrence of disabling conditions.

Many types of disabling conditions can be prevented. To reduce the incidence of disabling conditions in the Navajo Nation numerous service agencies must learn to work together more effectively, including the Indian Health Service, the Navajo Divisions of Social Welfare and Child Development, Health Improvement Services, the public schools, and the Bureau of Indian Affairs.

The basis of these efforts should revolve around community education:

- Community members, and especially fathers and expectant mothers, should be provided with information pertaining to the prevention of socio-environmental factors associated with disability (e.g., toxic substances, accidents, child abuse, substance abuse) and acqainted with means for arresting such conditions (e.g., first aid);

- Community members, and especially fathers and expectant mothers, should be provided with information pertaining to the prevention of bio-medical factors associated with disability (e.g., maternal health services, family planning, natal and neo-natal care, child health services, immunizations, screening and counseling for genetic disorders); and

- Students at all grade levels, from kindergarten through post-secondary programs, should be provided with information pertaining to the prevention of socio-environmental and biological factors associated with disability.

10. Support routine and timely diagnosis, screening and referral of children with disabling conditions.

Implementing this recommendation will help assure that all children with developmental disabilities, or "at risk of" such disability, are identified. Current initiatives to identify these children and to build computerized files regarding their status are commended. What remains to be done is to find effective means for:

- Early periodic screening and diagnostic treatment. The earlier potentially disabling conditions are identified and proper interventions are provided, the greater are the chances for the remediation or elimination of such conditions. For this reason, every Navajo child should have access to a "well child" clinic where appropriate screening and diagnostic services are provided according to national standards;

- Sharing information among concerned professionals. Present regulations for guarding the confidentiality of any information collected are well intended. However, professionals working with the same child or family are often denied easy access to useful information because of these rules. Systematic means should be devised that allow professionals to access the data they need, while the confidentiality of such information is not unduly compromised;

- Involving parents. Parents are the primary caregivers for their children. Consequently, their involvement in the identification and subsequent treatment of disabling conditions is essential;

- Developing a clearer understanding of service needs. Too often our understanding of the service needs of children and families is colored by the narrow focus of the attending professional. Children can have a wide range of needs, involving multiple disciplines. Likewise, no two families are alike, each having its own unique needs. To serve children and their families effectively, information regarding all their

potential needs, including their health related, developmental and family-based needs, must be compiled and reviewed; and

- Following cases as they evolve. The needs of children and families change with age and development. Thus, effective means must be employed to track children as they grow older to assure that they consisrently receive the services they need.

11. Provide children with disabilities needed health care, and developmental and habilitative intervention.

Members of the Blue Ribbon Panel advised that services be made available to all children with developmental disabilities in these three areas:

- Case management: Each child and family should be assigned a "case manager" whose charge is to assure continuity and appropriate comprehensiveness of care across all needed services. Such services could include individual assessment, planning, and a range of health or habilitative services as needed.

  For each child a case manager employed by one agency should be designated to coordinate and monitor the delivery of services. Such support shall include the education of family members regarding their rights and entitlements, securing access to available resources, developing new resources in areas with local deficiencies, and assistance with integrating the child with disabilities and his family into the community. Panel members felt that the most appropriate agency to undertake the case management role is the Tribal Division of Social Welfare which, with additional resources and training, could develop an effective case mamagement system.

- Health care services: Health care and health related services, including traditional healing practices, shall be equal in quality and scope to that available to any child in America. All children and their families shall have unrestricted access to health services. These include health care maintenance, preventive services, health education, diagnostic evaluation, rehabilitative services, chronic medical care and management, acute medical care, mental health care, and other specialty care. Moreover, available services should also include specialty training of primary caregivers, including family members, and the provision of special equipment in the home or surrogate home setting, or provision of medical or paramedical staff to provide necessary chronic care procedures away from the clinical setting.

  Essential to this area is the need to develop a common definition of and approach to "skilled care" among the following agencies: Indian Health Service, Bureau of Indian Affairs, Tribal Division of Social Welfare, the New Mexico Health and Environment Department, the Arizona Department of Health Services, and the Utah Division of Human Services. Such cooperation is long overdue and, as a result, numerous children with severe/profound disabilities have not received the timely services they need. The panel recommends that a "Memorandum of Agreement" be developed between relevant Tribal and state agencies specifically to

reach consensus over what is meant by "skilled care," to eliminate existing ambiguities in service roles, and to provide a coordinated and effective response to childhood disability.

- Educational services: The Education of the Handicapped Act (Public Law 94-142) mandates that children aged 5-21 years receive a free and appropriate public school education. As noted earlier, Congress has recently passed a similar measure, Public Law 99-457 (See Appendix A), keyed to children 0-5 years of age. To assure that Navajo children with disabilities receive the early intervention services they need, efforts must be made to prompt the timely implementation of this law in the Navajo Nation.

The implementation of Public Law 99-457 is similar in process to that used to intiate Public Law 94-142. Each state electing to participate in the program is required to submit a plan for implementing the law. As with Public Law 94-142, the Bureau of Indian Affairs (BIA) is considered a "51st" state for purposes of implementing the new mandate. Thus far, each of the three states serving the Navajo Nation, Arizona, New Mexico and Utah, have submitted the necessary plan for implementing Public Law 99-457. The BIA, however, has not yet submitted its plan.

To assure the provision of appropriate school services to Navajo children with disabilities, either through public schools or BIA programs, a "Memorandum of Agreememt" must be developed between the three relevant state offices of education, the BIA, and the Navajo Nation to address the following areas of concern:

1) Gaining access to early intervention services. To provide exemplary services to young Navajo children, certain barriers must be overcome, particularly for children for whom the BIA is responsible. One such barrier pertains to program eligibility. At present, for a student to become eligible for special education services, he or she must first be enrolled in a BIA school. This condition will be difficult for pre-school children to meet, given that currently the BIA does not offer pre-school services. This issue obviously must be addressed in the BIA plan for implementing Public Law 99-457.

2) Parental choice. Consistent with other recommendations, panel members were concerned over the role parents will play in the design of appropriate educational programs for their children with disabilities. Will parents have a choice concerning which agency will serve the educational needs of their children? Will parents have a say over the services their children receive?

3) The role of Headstart programs. Headstart programs serve many Navajo children aged 3-5 years, including several with disabilities. Given the advent of Public Law 99-457, what role, if any, will Headstart play in the service delivery system?

4) Cooperation among participating agencies. No single agency may offer all those services a particular child needs. In such cases, cooperative means must be found to assure that children receive all needed servicves. Likewise, where more than one agency offers a needed service, guidelines must be developed to assure an efficient use of resources.

- Developmental and Habilitative Services: Though numerous developmental and habilitative services may be offered as educational services through the public schools, care must be taken to assure that the full array of needed services is available. Examples of such services include: housing adaptations, provision of special equipment, physical therapy, communication/language instruction, counseling or behavior management, transportation, and instruction specifically aimed at facilitating developmental growth.

12. Strengthen and Enhance the Family Support System.

The purpose of this recommendation is to prompt the development and deployment of:

> a Navajo Nation initiative that enables Navajo families to provide home care to persons with disabilities and alleviates the costs, financial and emotional, incurred by families for providing such care.

The aims of such an initiative are to:

- strengthen the family's capacity to provide care;
- promote development of a family life that is as close as possible to that experienced by families without members with disabilities;
- prevent unnecessary out-of-home placement; and
- allow families, if they choose, to have their member with disabilities return home from an alternative placement.

At present, few programs in the Navajo Nation, if any, offer caregiving families the supports they need. Aside from those services designed for the child, these supports include, but are not limited to: information and referral, parent/sibling education, temporary relief or respite care, cash assistance, family counseling, and guidance for planning for the future. Such services, designed primarily for the family caregivers, have been shown elsewhere to have a positive effect on the child with disabilities and on the integrity of his or her family.

In addition, one area of needed family support that is unique to the Navajo Nation pertains to the overwhelming demand for adequate housing for families who provide home care to persons with disabilities. Due to the direct effect that adequate housing has on families' capacity to provide home care, panel

members strongly recommend that families who provide home care be given priority in housing allocations provided by the Navajo Tribe. Panelists also recommend that such prioritization be closely monitored by an effective advocacy system (See Recommendation 16) to assure that families with members having a disability will receive priority at the local level.

Overall, a family support program offers a comprehensive array of services designed to habilitate the child with disabilities directly and other services designed specifically to enhance the capacity of family members to provide care. A family centered approach results in multiple benefits:

- The family benefits because of an enhanced capacity to provide care and an improved quality of life;
- The child benefits because s/he is able to stay in a supportive home with more capable family caregivers; and
- The Navajo Nation benefits because it has strengthened the family structure and may realize some cost savings due to a diminished need to fund expensive alternative residential options.

To fund this type approach, at least six options should be explored:

- Utilize existing family support programs. The Navajo Nation could benefit from family support programs already operating in Arizona, New Mexico and Utah. Though these recent initiatives are modest in scope, policy makers in these states should be approached to develop coordinated means for involving Navajo families with these services;
- The Navajo Tribal Trust Fund. Family supports can, at least in part, be funded through interest earned through the recently created Navajo Trust Fund (See Appendix B);
- Federal grants. Pilot family support projects could be funded by federal grants made available through such agencies as the Administration on Developmental Disabilities or the National Institute for Disability and Rehabilitation Research. To develop competitive grant proposals staff at the Navajo Community College or the two Native American Rehabilitation Research and Training Centers in Arizona could prove most helpful. One chronic problem associated with this tactic, however, pertains to the short term nature of projects funded through federal grants. If this approach is pursued, care must be taken to assure that projects will remain funded even after federal support ceases;
- Titles XIX and XX of the Social Security Act. Panel members indicated that Title XX dollars, presently received by the Tribal Division of Social Welfare and the Bureau of Indian Affairs, are not currently

targeted to support home care, but instead are used primarily to support out-of-home placements. Navajo officials should review the regulations governing these funds, and may find means for applying these dollars to family support services. Similarly, Navajo officials should investigate the potential use of Title XIX funds through a "community based waiver." New Mexico has obtained such a waiver and may be willing in future years to offer family support services through a waiver program to Navajo families;

- Existing Navajo Tribal programs. Not all family support services must be created from scratch. Many useful Navajo programs already exist that could be targeted to families who provide home care. Setting priorities regarding housing allocations to favor caregiving families was noted earlier. Similarly, panel members suggested that respite care could be provided through the existing "welfare to work" program or the Tribal Work Experience program, simultaneously providing parents with useful job skills. Also, funds available through the BIA and targeted to social services can be used. Though these dollars presently are allocated to sponsor out-of-home treatment approaches, a portion of these funds might instead be used to support home care; and

- A combination of approaches. All the approaches noted above can be used in combination to build a comprehensive family support program in the Navajo Nation. To do so, however, program planners must carefully weigh the strengths and weaknesses of each tactic and devise systematic means for taking their full advantage.

E. Program Practice: Administrative Support

Over the past several years, the reform of service systems has too often moved forward without the proper administrative basis to support changes in approach and practice. The negative consequences of such decisions, however, well intended, are well documented. Systems with a weak administrative base lack the capability to improve or expand services systematically, frustrating policymakers and service providers alike. Ultimately, the system's capacity for achieving desired ends is compromised, to the dismay of all concerned parties.

Crucial to assuring the success of the proposed plan is the development of an underlying base of information, personnel, quality controls, and a protection and advocacy system to support the service reform process and any new services that emerge for the long term. In this light, four recommendations are offered.

13. Develop an improved information system to identify and track children with disabilities and their families.

Present efforts to track persons with disabilities using computerized means are commended. Building on these efforts, a more comprehensive client information system should be designed and deployed that is especially suited to young children and their families. Made an integral part of the individual planning process, the information collected should be sufficient to assess the adequacy and appropriateness of the services offered, and the urgency of any need for alternative programs. Moreover, collected information could be used to support systematic planning efforts, especially if commonly accepted definitions of key terms (e.g., developmental disability) were developed.

Systems of service delivery are ever changing in response to new clients or changes in habilitative practice. Such change can be planned in advance to some extent, given accurate information on the past and present status of services. Information collected on children with disabilities could be aggregated so that: 1) the effectiveness of rendered services could be assessed, 2) changes in the status of clients or services offered could be tracked, and 3) applications for supplemental funding (e.g., federal grants) could be strengthened.

To generate sufficient information, multiple measures covering the child's and family's status may need to be employed. Wherever possible existing instruments with proven utility should be used. For instance, the state of Utah currently uses the Battelle Screening Test to assess the functional capabilities of young children. An important benefit of using a pre-existing instrument is the ability to compare the characteristics of Navajo children with national norms. If this practice were implemented, however, any cultural biases of the measure used would require careful consideration.

14. Develop means for monitoring and assuring the quality of provided services.

Assuring the quality of those services offered is a necessary component of any service system. It is an element that, in many states, has been inadequately developed and unevenly applied. In too many instances, quality assurance resources have been cut back at a time when community programs are expanding or undergoing reform, which in turn has significantly handicapped program oversight.

Given a commitment to improving services in the Navajo Nation for children with disabilities, the development of sound quality control practices is essential. To be successful, quality assurance systems must satisfy several objectives, ensuring that:

- services are provided consistent with accepted professional practice;
- service providers have the capacity to provide an acceptable level of services;
- a commitment of resources produces a reasonable level of service;
- services provided have the intended effect; and
- services are provided to those most in need.

The major ingredients of a quality assurance system include: program standards, monitoring systems, and control and program enhancement activities (e.g., staff training). To be successful, quality assurance mechanisms must both regulate as well as enhance service quality.

As the Navajo Nation moves to improve its response to childhood disability, panel members recommend that existing quality control practices be reviewed. Where needed such practices must be altered or expanded. Further, panel members suggest that a review team be formed whose composition includes parents, professionals in early childhood, and client advocates whose function would be to assess the quality of services to children with disabilities and their families. Over time, the resulting system of controls will help assure

that children with disabilities and their families receive needed services that are of the highest quality.

15. Develop an improved means for recruiting and preparing direct care staff.

The success of the Navajo Nation's response to childhood disability is dependent on its capability to assure that quality care is provided within the most appropriate settings. In this regard, the recruitment, retention and development of competent staff is crucial, including early intervention specialists, parent educators, physical and language therapists, and trained basic care aides. Policymakers, however, often overlook the importance of establishing effective staff recruitment and support mechanisms, focusing instead on enhancing direct service capabilities.

Assuring the availability of competent staff in the the Navajo Nation is a troublesome task. Family members, service professionals, and administrative staff consistently note the ongoing difficulty with recruiting appropriate staff. Any thought of expanding present service capabilities must be tempered by this sobering reality.

These conditions, however, are not necessarily permanent. Steps should be taken to build a "human services industry" in the Navajo Nation that focuses first on developing basic care paraprofessionals with fundamental, yet essential, skills pertaining to early intervention and family education. Such persons may take on formal responsibilities as employees of service agencies or less formal roles, offering only periodic assistance as needed. These persons can: 1) staff center-based early intervention programs, 2) provide families with temporary relief from their caregiving responsibilities, and 3) deliver specialized interventions under the direction of professional staff. More importantly, from this pool of workers persons will likely emerge who are willing to further their knowledge and acquire specialized competencies through participation in a formalized career training program.

In addition to these efforts, an attempt must also be made to assure the availability of a range of professional health-related, habilitative, and specialty staff. Although difficulties with recruiting and retaining such staff in the Navajo Nation are well documented, further exploration of this issue is essential because such staff are crucial to improving current service practices. Every effort must be made to understand this problem and to develop a plan for its solution.

Key to building a "human services industry" are the area's centers for vocational instruction and higher education. The Navajo Community College, located in the western sector of the Navajo Nation, and the Crownpoint Institute of Technology, located in the east, represent valuable resources that could act as staff training centers. Likewise, the two Native American Rehabilitation Research and Training Centers in Arizona can also help. One is located at Northern Arizona University in Flagstaff, while the other is at the University of Arizona at Tucson. These centers are charged with undertaking useful research and with offering training to staff persons in their area. Finally, the value of existing programs (e.g., McKinley Area Services for the Handicapped in Gallup) should not be overlooked. These programs may be used as on-the-job training sites.

Other possible resources for staff preparation were identified by panel members. Primary among them are scholarships made available for Indian college students through the Indian Health Care Improvement Act (Public Law 96-437). Presently, the funding categories exclude habilitative fields like physical, occupational, and speech therapy in spite of the great need for Indian professionals in these areas. Panel members strongly recommend that occupations in habilitative and related fields be added to those career training categories served by these scholarships. Similarly, panelists suggest the establishment of special scholarships for training in the habilitative and

special education fields by the Navajo Department of Higher Education and/or the Navajo Education Foundation as another way to attract other students. Other suggestions included establishing a cooperative network among service providers, universities, and institutes or foundations (e.g., the Alfred I. Dupont Institute, J.F. Kennedy Institute for the Handicapped) whereby needed specialized personnel could be obtained and shared among programs. Such specialized personnel could provide a variety of technical assistance, such as specialized dentistry for children with disability, training in specialized habilitative topics for parents and service providers.

Overall, many of the tools needed to recruit and train needed staff are already available. What is needed is a commitment of resources and a sound plan for taking their full advantage.

16. Develop an effective protection and advocacy system.

Although each of the three states overlapping the Navajo Nation offer protection and advocacy services to persons with disabilities, these services have not been available to residents of the Navajo Nation. Such services are unavailable due to a variety of reasons, including: 1) logistical barriers related to the geographic distances between population centers, 2) differences in culture and language that sometimes make it difficult to apply practices accepted in each state to the Navajo Nation, and 3) the complexities associated with the bounds of state and Navajo tribal court juristictions and the status of the Navajo Nation as a sovereign entity.

The unique nature of these combined circumstances has prompted the panel to recommend with great urgency that the Navajo Nation establish its own protection and advocacy system to assure the protection of the rights of all Tribal members with disabilities and their families. Further, the panel recommends that such a system be independent of governmental entities and direct service agencies in order to assure a true advocacy function. A Navajo

based protection and advocacy system could obtain operating funds either from an appropriate federal agency (e.g., the Administration on Developmental Disabilities), from interest earned from the recently initiated Tribal Trust Fund (if necessary), or from some combination.

F. Concluding Remarks

Present discussion in the Navajo Nation regarding the services to children with disabilities and their families, and how they can be improved is needed and most welcome. Such discussion often grows lively in the face of the complex decisions that must be made and the overriding concern that children receive the services they require. Yet the commitment among many to the development of a superior system of services is in plain view.

The preceding recommendations suggest that building a viable delivery system to serve children with disabilities and their families will require the cooperation of many, including persons with disabilities, family members, neighbors, policy makers at all levels, and professionals working both in the public and private sector. At the core of their efforts must be a firm resolve to forge an effective partnership among all those concerned whose purpose is to offer services of the highest quality to children with disabilities within the most appropriate settings. It is our hope that this report and the above recommendations will provide needed information and stimulate further discussion directed at achieving this worthwhile end.

REFERENCES

Agosta, J.M., Bass, A. & Spence (1986). The needs of families: Results of a statewide survey in Massachusetts. Cambridge, MA: Human Services Research Institute.

Agosta, J.M., Jennings, D. & Bradley, V.J. (1985). Statewide family support programs: Results of a national survey. In J.M. Agosta and V.J. Bradley (Eds.), Family care for persons with developmental disabilities: A growing commitment. Cambridge, MA: Human Services Research Institute.

Apolloni, A.H. & Triest, G. (1983). Respite services in California: Status and recommendations for improvement. Mental Retardation, 21, 240-243.

Ashbaugh, J., Spence, R., Lubin, R., Houlihan, J. & Langer, M. (1985). Summary of data on handicapped children and youth. Cambridge, MA: Human Services Research Institute.

Backman-Bell, P. (1981). Parents perspectives. In J. Paul (Ed.), Understanding and working with parents of children with special needs. New York, NY: Holt, Rinehart and Winston.

Bayley, M. (1973). Mental handicap and community care. London, United Kingdom: Routledge and Kegan Paul.

Bernard, K. (1975). Trends in the care and prevention of developmental disabilities. American Journal of Nursing, October, 1700-1704.

Brehon Institute for Human Services (1985). Whom shall we serve? A policy study on the application of a functional definition of developmental disabilities in seven Florida programs. Tallahassee, FL: Florida Developmental Disabilities Planning Council.

English, R.W. & Olson, K.K. (1978). Parenting and handicapped children: Their earliest experiences. The Journal for Special Education, 15, 10-17 and 169-186.

Fischler, R.S. & Fleshman, C. (1985). Comprehensive health services for developmentally disables Navajo children. Journal of Develoopmental and Behavioral Pediatrics, 6(1), 9-14.

Fleshman, C. (1983a). Prevalence of selected disabilities among young Navajo children. In C. Fleshman (Ed.), Selected research papers from the Dine Center for Human Development. Navajo Nation, AZ: Navajo Community College-Tsaile; Dine Center for Human Development.

Fleshman, C. (1983b). The Denver Developmental Screening Test for Navajo preschool children. In C. Fleshman (Ed.), Selected research papers from the Dine Center for Human Development. Navajo Nation, AZ: Navajo Community College-Tsaile; Dine Center for Human Development.

Fortier, L.M. & Wanlass, R.L. (1984). Family crisis following the diagnosis of a handicapped child. Family Relations, 33, 13-24.

Frankenburg, W.K. & Dodds, J.B. (1967). The Denver Developmental Screening Test. Journal of Pediatrics, 71, 181-191.

Gliedman, J. & Roth, W. (1980). The unexpected minority: Handicapped children in America. New York, NY: Harcourt, Brace and Javanovich.

Hauber, F.A., Bruininks, R.H., Hill, B.K., Lakin, K.C., & White, C.C. (1982). National census of residential facilities: Fiscal Year 1982. Minneapolis, MN: University of Minnesota, Department of Educational Psychology.

Indian Health Services (1985). Indian health services: Chart series book. Rockville, MD: Indian Health Service; Office of Planning, Evaluation and Legislation; Program Statistics Branch; Parklawn Building.

Joe, J.R. (1980). Disabled children in Navajo society (Doctoral dissertation, University of California at Berkeley and San Francisco). Ann Arbor, MI: University Microfilms International.

Konanc, J.T. & Warren, N.J. (1984). Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. Family Relations, 33, 135-142.

Kozak, A.E. & Marvin, R.S. (1984). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33, 67-78.

Longo, D.C. & Bond, L. (1984). Families of the handicapped child: Research and practice. Family Relations, 33, 57-66.

Lonsdale, G. (1978). Family life with a handicapped child: The parents speak. Child Care, Health and Development, 4(2), 99-120.

McAndrew, I. (1976). Children with a handicap and their families. Child Care, Health and Development, 2, 213-237.

NAIHS Area Rehabilitation Office (1986). Resource directory for services in Navajo area for developmentally delayed, physically handicapped children and youth. Navajo Nation: Navajo Tribe Division of Social Welfare.

NAIHS Office of Planning and Development (1980). Navajo Nation master health plan: Health status chapter. Navajo Nation: Navajo Indian Health Service

New Mexico State Department of Education (1986). Educational standards for New Mexico Schools; SBE Regulation No. 85-4, Amendment No. 2 (Exhibit A). Sante Fe, NM: State Department of Education.

Suelzle, M. & Keenan, V. (1981). Changes in family support networks over the life cycle of mentally retarded persons. American Journal on Mental Deficiency, 86, 267-274.

Tausig, M. (1985). Factors in family decsion-making about placement for developmentally disabled individuals. American Journal on Mental Deficiency, 89, 352-361.

Toubbeh, J.I. (1985). Handicapping and disabling conditions in Native American populations. American Rehabilitation, Jan-Feb-March, 3-8, 30-31.

Turnbull, A., Summers, J. & Brotherson, M. (1985). Family life cycle: Theoretical and empirical implications, and future directions for families with mentally retarded members. In J. Gallagher and P. Vietze (Eds.), Research on families with retarded children. Baltimore, MD: University Park Press.

Wikler, L. (1983). Chronic stress of families of mentally retarded children. In D.H. Olson & B.C. Miller (Eds.), Family studies review yearbook (Vol. 1). Beverly Hills, CA: Sage Publications.

APPENDIX A:

PUBLIC LAW 99-457:
EARLY INTERVENTION PROGRAM

NEW FEDERAL PRESCHOOL PROGRAM UNDER P.L. 99-457

All the rights and protections of P.L. 94-142 (EHA, Part B) are extended to handicapped children ages three through five years in school year 1990-91. To support the achievement of this objective, the prior Preschool Incentive Grant program (P.L. 94-142, Sec. 619) is revised to reflect authorization of a dramatic increase in the federal fiscal contribution for this age group.

- By school year 1990-91, all states applying for P.L. 94-142 funds will have to assure that they are providing a free appropriate public education to all handicapped children ages three through five. Failure to comply will mean the loss of the following:

  - the new Preschool Grant;
  - monies generated under the larger P.L. 94-142 formula by the three through five population served; and
  - grants and contracts related to preschool special education authorized under the EHA discretionary programs, Parts C through G.

- The states are not required to report children served three through five years by disability category. Thus the states are not required to categorically label these children because of the data collection requirements of EHA, Sec. 618.

- The committee report accompanying the legislation states that family services play an important role in preschool programs and that whenever appropriate and to the extent desired by the parents, the preschooler's individualized education program (IEP) will include instruction for parents.

- The committee report affirms variations in length of school day and range and variety of preschool programs, examples being part-day home-based, and part or full-day center-based.

- This program will be administered through the state education agency and local education agencies. However, SEA's and LEA s may contract with other programs, agencies, and providers in order to provide a range of service models.

- The federal authorization levels are: (track a) $300 for each 3 through 5 year old handicapped child served in the previous school year; and (track b) a maximum of $3,800 for each 3 through 5 year old the state intends to serve in the coming year beyond the previous year's count. These are authorization levels only. The Congress must still appropriate the actual amounts each year, commencing this year.

The basic amount authorized under track a escalates:

- FY 87 (school year 87-88) $300 per child
- FY 88 (school year 88-89) $400 per child
- FY 89 (school year 89-90) $500 per child
- FY 90 (school year 90-91) $1,000 per child (track b for unserved ends)
- thereafter $1,000 per child

(Over)

In each year, children counted as unserved (track b) are only those beyond the previous year's count. Children counted in the first year under track b would generate funds under track a in the second year.

Example:

1st year — State A serves 1,000 3-5 year olds this year and reports it will serve 250 more in first year. Under formula state A receives:

1,000 x $300	=	$ 300,000
250 x $3,800	=	$ 950,000
		$1,250,000

2nd year — Serves 1,250 3-5s in first year. Reports it will serve 250 more in second year. Under formula state A receives:

1,250 x $400	=	$ 500,000
250 x $3,800	=	$ 950,000
		$1,450,000

3rd year — Serves 1,500 3-5s in second year. Reports it will serve 250 more in third year. Under formula state A receives:

1,500 x $500	=	$ 750,000
250 x $3,800	=	$ 950,000
		$1,700,000

4th year — Serves 1,750 3-5s in third year. Must be serving all children by then. Under formula state A receives:

1,750 x $1,000 = $1,750,000

- The full service mandate is delayed for one year until school year 1991-92 if:
  - federal appropriations for this program for FY '87, '88, and '89 do not total $656 million (projected full funding); and
  - the federal appropriation for FY '90 is less than $306 million ($900 per child)
- The in-state distribution of federal funds under this new Preschool Grant is:
  - FY '87 — 5% SEA Administration
    25% SEA Discretion
    70% LEA's and IEU's (IEU - Intermediate educational unit)
  - FY '88 and beyond — 5% SEA Administration
    20% SEA Discretion
    75% LEA's and IEU's

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NEW FEDERAL EARLY INTERVENTION PROGRAM UNDER P.L. 99-457

Objective

Establishes a new state grant program for handicapped infants and toddlers, ages birth through two years, for the purpose of providing early intervention services for all eligible children as defined by the legislation. This program appears as a new Part H of the existing Education of the Handicapped Act (EHA).

Eligible Population

The legislation defines the eligible population as all children from birth through two years of age who are developmentally delayed (criteria to be determined by each state), or with conditions that typically result in delay, or (at state discretion) are at risk of substantial developmental delay.

Timelines

To receive a grant for the:

First Two Years: The Governor must designate a lead agency (there is state discretion respecting which agency is designated) for overall administration of the program.

The Governor must also establish an Interagency Coordinating Council composed of relevant agencies, consumers, and providers. This Council is to assist in the development and implementation of the state applications, as well as assist in interagency agreements and the identification of resources, and is to otherwise advise the state. The Council may also serve as the lead agency.

Third Year: The state must demonstrate that it has adopted a public policy which provides all of the components of a statewide system for providing early intervention services to all eligible infants and toddlers.

Fourth Year: The state must demonstrate that it has in effect a statewide system for providing early intervention services. The state must also provide for all eligible children the following: multidisciplinary assessments, individualized family service plans, and case management services.

Fifth and All Succeeding Years: The state must make available to all handicapped infants and toddlers within the state appropriate early intervention services.

Early Intervention Services

Early intervention services must include, for each eligible child, a multidisciplinary assessment and a written Individualized Family Service Plan (IFSP) developed by a multidisciplinary team and the parents. Services

(Over)

which may be provided must be designed to meet developmental needs and may include special education, speech and language pathology and audiology, occupational therapy, physical therapy, psychological services, parent and family training and counseling services, transition services, medical services for diagnostic purposes, and health services necessary to enable the child to benefit from other early intervention services. Case management services must be provided for every eligible child and his/her parents.

All early intervention services must be provided at no cost to parents except where federal or state law provides for a system of payments by parents, including provision for a schedule of sliding fees.

The Individualized Family Service Plan (IFSP)

The IFSP must contain: (a) a statement of the child's present levels of development (cognitive, speech/language, psychosocial, motor, and self help); (b) a statement of the families strengths and needs relating to enhancing the child's development; (c) a statement of major outcomes expected to be achieved for the child and family; (d) the criteria, procedures, and timelines for determining progress; (e) the specific early intervention services necessary to meet the unique needs of the child and family including the method, frequency and intensity of service; (f) the projected dates for the initiation of services and expected duration; (g) the name of the case manager; and (h) procedures for transition from early intervention into the preschool program.

The IFSP must be evaluated at least once a year, and must be reviewed every six months or more often where appropriate.

Use of EHA Funds

Federal funds under this program are to be used for the planning, development, and implementation of the statewide system for provision of early intervention services. Funds may also be used for the general expansion and improvement of services. However, in the provision of actual direct program services, federal funds under this program shall be the "payor of last resort," i.e., EHA funds may not be used when there are other appropriate resources which can be used or are being used, whether public or private, whether federal, state, or local. This provision emphasizes the critical importance of achieving efficient and effective interagency participation in each state.

Other Provisions of the New Law

- Each state must submit an annual application which includes the necessary assurances based upon the timetable just mentioned. At the appropriate time, that annual application must specify the role and financial contribution of each participating agency and must provide a description of the state's procedural safeguard system when complaints are brought by parents.

- Funds under this program will be allocated to the states based upon their relative number of children birth through two years, i.e., a census-based allocation and not an allocation based upon numbers of children served. Fifty (50) million dollars is authorized for fiscal year 1987, $75 million for fiscal year 1988, and "such sums as may be necessary" for the following years.

- Provision of all services must be by qualified personnel, and the state must have a system for the establishment and maintenance of standards, certification, and licensing policies.

- The state planning, development, and implementation grants under the prior EHA, Part C, (as authorized in P.L. 98-199) are repealed. The committee report accompanying P.L. 99-457 emphasizes that the activities under that previous authority will continue to be supported under this new EHA, Part H, as well as under the new Preschool Grant.

- The U.S. Secretary of Education and the U.S. Secretary of Health and Human Services are required to conduct a joint study of federal funding sources and services for early intervention programs and are ordered to facilitate interagency coordination of federal resources. They are to report their findings and actions to the Congress within 18 months from the enactment of P.L. 99-457.

EARLY EDUCATION DISCRETIONARY PROGRAM
EHA, PART C, SEC. 623 (also known as HCEEP)

P.L. 99-457 reaffirms the proven components of EHA, the Part C early education authority and refines that authority to maximize support toward achieving the objectives of the new early intervention and preschool initiatives.

- Experimental, demonstration, and outreach programs are authorized, with priority given to outreach and demonstration with respect to three through five year old children.

- Projects designed to demonstrate cost effective methods are encouraged.

- A technical assistance developmental system is authorized, which system shall provide support to the experimental, demonstration, and outreach programs under this authority as well as support to state agencies.

- Early childhood research institutes are authorized to carry out sustained research to generate and disseminate new information on early education.

- The state planning, development, and implementation grants authorized through P.L. 98-199 are repealed in light of the new EHA, Part H, and the revised EHA, Sec. 619.

EDUCATION OF THE HANDICAPPED ACT (EHA)
FISCAL 1987 APPROPRIATIONS IN RELATION TO FISCAL 1986 APPROPRIATIONS
AND FISCAL 1987 AUTHORIZATIONS
(in millions)

	FY 1986 Appropriations* (With 4.3% Sequestration)	FY 1987 Authorizations	FY 1987** Appropriations
EHA			
• P.L. 94-142 State Grants	$1,163.28	formula	$1,338.00
• Preschool Grants	28.71	formula	180.00
• Early Intervention Initiative	---	50.00	50.00
• Deaf-Blind Centers	14.12	15.90	15.00
• Severely Handicapped Projects	4.78	5.30	5.30
• Early Childhood Education	22.96	24.47	24.47
• Secondary Education and Transitional Services	6.32	7.30	7.30
• Postsecondary Education Programs	5.26	5.90	5.90
• Innovation and Development	16.08	18.00	18.00
• Technology	---	10.00	3.50
• Captioned Films and Educational Media	16.67	15.00	15.00
• Regional Resource Centers	6.02	6.70	6.70
• Clearinghouses	1.06	1.20	1.20
• Personnel Development	61.15	70.40	67.70
• Evaluation and Special Studies	3.09	3.80	3.80
EHA Total	$1,349.50		$1,741.87
Chapter 1 (P.L. 89-313)			
• State Operated Programs-Handicapped	$143.71	formula	$150.17

*March 1, 1986, sequestration under the authority of Gramm-Rudman-Hollings (G-R-H).
**Final House and Senate agreement.

Prepared by
Department of Governmental Relations
The Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
October 16, 1986

APPENDIX B:

RESOLUTION OF THE NAVAJO TRIBAL COUNCIL ESTABLISHING FOUR PERMANENT TRUST FUNDS

CD-68-86

Class "B" Resolution
Area Approval Required.

RESOLUTION OF THE
NAVAJO TRIBAL COUNCIL

Establishing and Authorizing Four (4) Permanent Trust Funds; and Approving the Appropriation of $21,000,000, Utilizing Undesignated Tribal Reserves Above the $55,000,000 Required Minimum Fund Balance as Initial Contribution to the Trust Funds

WHEREAS:

1. The Navajo Tribal Council is the governing body of the Navajo Nation; and

2. In accordance with Tribal Law, as stipulated in Navajo Tribal Council Resolution CS-45-84, "Resolved clause", paragraph 2, subparagraph (o):

> "The 'Unappropriated Surplus Fund' shall be redesigned as the 'Tribal Reserve Fund' and this fund will be allowed to build back up to the level of $55 Million and maintained at that level as the minimum fund balance.";

and

3. The "Unaudited" Year-End Financial Statements for Fiscal Year 1986, dated September 30, 1986, shows that the required "minimum fund balance" for Tribal Reserves is exceeded by $43,900,000; therefore, resulting in sufficient "undesignated Tribal Reserve Funds" to support the proposed Supplemental Appropriation of $21,000,000 as detailed in Exhibit "A", attached hereto and incorporated herein; and

4. Further, in accordance with Navajo Tribal Council Resolution CS-53-86, "Resolved clause", paragraph 3, subparagraph g:

> "There shall be no budget resolutions (for budget transfer, supplemental and/or new appropriations), during the first quarter of Fiscal Year 1987...",

and this provision must be waived by the Navajo Tribal Council, in order for the "Supplemental Appropriation" to be considered by the Navajo Tribal Council.

NOW THEREFORE BE IT RESOLVED THAT:

1. The Navajo Tribal Council hereby "waives" the first quarter prohibition on budget Resolution (CS-53-86; Resolved clause, paragraph 3, subparagraph g) in order to consider the Supplemental Appropriation contained herein.

2. The Navajo Tribal Council further hereby appropriates $21,000,000, utilizing "Undesignated Tribal Reserves" above the required "minimum fund balance" of $55 Million for the purposes detailed in Exhibit "A", attached hereto and incorporated herein.

3. The Navajo Tribal Council hereby establishes and authorizes the Navajo Nation Trust Fund for Handicapped Services, as outlined in Exhibit "B", attached hereto and incorporated herein.

4. The Navajo Tribal Council hereby establishes and authorizes the Navajo Nation Trust Fund for Vocational Education, as outlined in Exhibit "C", attached hereto and incorporated herein.

5. The Navajo Tribal Council further hereby establishes and authorizes the Navajo Nation Trust Fund for Senior Citizens (Elderly) Services, as outlined in Exhibit "D", attached hereto and incorporated herein.

6. The Navajo Tribal Council further hereby establishes and authorizes the Navajo Nation Trust Fund for Navajo Academy Operations, as outlined in Exhibit "E", attached hereto and incorporated herein.

7. The Navajo Tribal Council further directs the Tribal Administration departments, programs and officials to continually seek additional State, Federal and private sources for matching funds to help supplement the programs.

CERTIFICATION

I hereby certify that the foregoing resolution was duly considered by the Navajo Tribal Council at a duly called meeting at Window Rock, Navajo Nation (Arizona), at which a quorum was present and that same was passed by a vote of 58 in favor, 5 opposed and 3 abstained, this 12th day of December, 1986.

Peter Zah

Chairman
Navajo Tribal Council

EXHIBIT "A"

1. Handicapped Trust Fund..... 7,000,000

Because of the lack of sufficient services provided to the Navajo Nation's Handicapped citizens, a request is being made to establish a permanent type of trust fund for the purposes of providing grants to programs and organizations outside of the Tribal Government who provide services to the Handicapped. The initial investment of $7,000,000 will be managed in accordance with the Plan of Operation contained in Exhibit "B". It is estimated $400,000 will initially be made available on an Annual Basis for program/project grants for Handicapped Services.

2. Vocational Education Trust Fund..... 6,000,000

The Navajo Tribal Council on August 27, 1986, adopted Resolution CAU-50-86, providing for various supplemental appropriations during FY-86. Contained within these supplemental appropriations was an appropriation of $500,000 for initiating a Vocational Education Scholarship Program. These funds were needed to provide Scholarship Grants to Navajo Students wishing to attend Vocational Education Institutions. In order to continue the Vocational Education Scholarship Grant program, there is a need to establish a permanent type of trust fund for the purposes of providing such Vocational Education Scholarship Grants on an annual basis. The initial investment of $6,000,000 will be managed in accordance with the Plan of Operation contained in Exhibit "C". It is estimated $342,000 will initially be made available on an annual basis for Vocational Education Scholarship Grants.

3. Elderly/Senior Citizens Trust Fund..... 7,000,000

Because of the lack of sufficient services provided to the Navajo Nation's Elderly citizens, a request is being made to establish a permanent type of trust fund for the purposes of providing grants to programs and organizations outside of the Tribal Government who provide services to the Elderly. The initial investment of $7,000,000 will be managed in accordance with the Plan of Operation contained in Exhibit "D". It is estimated $400,000 will initially be made available on an Annual Basis for program/project grants for Elderly/Senior Citizens Services.

4. Navajo Academy Trust Fund.....1,000,000

This appropriation will provide funding for the establishment of a Permanent Trust for the Navajo Academy which will be managed in accordnance with the Plan of Operation contained in Exhibit "E". It is estimated $57,000 will initially be made available on an Annual Basis for School Operations at Navajo Academy.

TOTAL SUPPLEMENTAL APPROPRIATIONS $21,000,000

Exhibit "B"

Establishing and Authorizing the
Navajo Nation Trust Fund for Handicapped Services

SECTION 1. Establishment.

There is hereby established, the "Navajo Nation Trust Fund for Handicapped Services" [hereinafter called the "Fund"], with an initial appropriation of $7,000,000 as approved by the Navajo Tribal Council. Additional appropriations may be made from time to time by the Navajo Tribal Council provided that additional sources of revenue and/or funds are available for appropriation. Any money deposited into the Fund, plus accrued interest, shall be used only as provided hereinafter.

SECTION 2. Investment of the Fund.

All amounts of money deposited in the Fund shall be invested as soon as practical in accordance with Investment Objectives and Investment Policies of the Navajo Nation as formally adopted by the Budget and Finance Committee of the Navajo Tribal Council.

SECTION 3. Definition of Principal and Income.

(a) Fund Principal shall consist of all Navajo Tribal Council appropriations made pursuant to the Tribal Appropriation Processes and Procedures; and any contributions made by any parties or entities.

(b) Fund Income shall consist of all earnings (interest, dividends, etc.) generated by the Principal of the Fund.

SECTION 4. Expenditure of Fund Principal.

Fund Principal shall not be expended except pursuant to a referendum adopted by a two-thirds vote of all registered Navajo Voters. The Navajo Tribal Council may place a Referendum to Expend Fund Principal on the ballot of any primary, general or special election by a two-thirds vote of the full membership of Navajo Tribal Council.

SECTION 5. Expenditure of Fund Income.

(a) Ninety-Five percent (95%) of the Fund Income shall be used as Tribal Grants to supplement non-Tribal Government programs and projects who provide services to the Navajo Handicapped Citizens. Five percent (5%) of the Fund Income shall be reinvested in the Fund to cover the rate of inflation.

(b) Tribal Grants to non-Tribal Government programs and projects shall be awarded in accordance with rules and regulations developed by the Office of the Chairman and Vice-Chairman in consultation with the Health and Human Services Committee of the Navajo Tribal Council and approved by the Advisory Committee of the Navajo Tribal Council.

SECTION 6. Annual Audited Report.

The Fund shall be audited annually by independent outside auditors. Within ninety (90) days of the end of each Fiscal Year, an audit report shall be distributed to the members of the Navajo Tribal Council and interested members of the Navajo Public. The report shall be written in easily understandable language. The report shall include financial statements, a statement of the amount of money received by the Navajo Nation Trust Fund for Handicapped Services from each investment during the period, a statement of investments of the Fund including an appraisal at market value, a description of Fund investment activity during the period covered by the report, a statement of the Fund performance and other information relevant to the management of the Fund.

SECTION 7. Amendments.

Any Section or sections herein may be amended by the majority vote of the full membership of the Navajo Tribal Council except that Section 4 may only be amended as provided for in Section 4.

SECTION 8. Expenses.

All expenses directly associated with the administration and management of the Fund shall be paid from the Fund Income as approved by the Budget and Finance Committee of the Navajo Tribal Council. Such expenses shall include investment advisory and management fees, audit costs and other related expenses, all pursuant to duly approved contracts for such services.